Evidence Based Scan for My Health My Community

Pennine Care NHS Foundation Trust

Education and support for carers of people at the end-of-life

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Author: Dr Valerie A Featherstone

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Executive summary

Aims

- To identify issues for carers in end-of-life care
- To identify and appraise any structured educational programmes for carers of people at the end of their life
- To identify and advise on any gaps in the initial My Health My Community (MHMC) educational programme proposed by Pennine Care NHS Foundation Trust.

Methods

Following the initial scan, an in-depth search was undertaken to reinforce our initial findings and to explore further provision for carers. The approach taken is pragmatic and uses principles of 'evidence scans' (The Health Foundation 2010) and will be thus termed as such. This approach provides information to help those involved in improving the quality of healthcare to understand what research is available on particular topics. The purpose is to provide a synopsis of evidence to help inform discussions and to help identify if there is need for further research or development in the area covered. It will therefore provide a collation of empirical research about education/training/other initiatives for those in attendance of people at the end of their life.

A flag system designed by the reviewer has been used to appraise the attributes of programmes and initiatives. This appraisal is based on the evidence available on each initiative and offers a rapid guide to services, initiatives, ideas and resources available or in development. These are then expanded upon individually in the scan.

In addition recommendations in red boxes are also red flags for Pennine Care NHS Foundation Trust

Preparing caregivers will be a major consideration to address in the education programme. This appears to constitute a significant gap. Some existing carer training has been identified and a number of 'good practice models' are presented for Pennine Care NHS Foundation Trust to consider. Existing written and web based resources are described. End-of-life (EoL) guidelines, pathways and mandatory support for carers have been outlined and the issue of training health care professionals (HCPs) in EoL issues is important to address. Black, Asian and minority ethnic (BAME) and lesbian, gay, bisexual and transgender (LGBT) carers have also been considered. Finally, recommendations for training, supporting and educating carers have been suggested, coupled with a mapping exercise to identify gaps and prove alternative options for the proposed MHMC programme.

In terms of delivering a programme, one size does not fit all and carers will require different formats of support and training depending on their situation and individual preferences. This can include a guidebook on providing support to their friend/relative, others may prefer structured face to face psycho-educational interaction, one to one or in a group and there is potential for web based programmes. Some family caregivers will need more comprehensive, focused interventions based on thorough assessments.

Section 1. Brief scoping scan

The first phase of the evidence based scan (EBS) included an initial explorative, broad scoping of the literature to help define the focus and parameters of the EBS in order to inform discussions with Pennine Care NHS Foundation Trusts, My Health, My Community (MHMC) project team. Dates searched were from 2009 to 2014. Findings offered up topics and approaches to be explored further in subsequent phases. For example, a main finding was that carers are often unprepared for their role (Henriksson and Arestedt 2013). The parameters of the scoping scan are presented below.

Table 1. Search parameters

Resources searched	Search Terms Used
UoM library search PsychInfo Embase Evidence based medicine reviews Google scholar Google Grey literature	*'needs of lay-carers at end of life'* *'lay-carers'* *'UK carers'* *'informal carers'* *'end of life'* *'psychological needs'* *'needs of family'* *'psychological health'* *'reviews'* *'systematic reviews'*

Sources identified included peer reviewed academic papers, general reviews; general EoL literature; instruments, assessments, measures and evaluations, resources, guidelines and interventions. Numerous grey literature and internet sites including NHS, government documents, NICE, palliative care national and international organisations and conference papers and presentations were accessed. Forums and blogs were also identified and could be useful resources for them. Some disease specific papers were identified and these are reviewed in separate EBS' which accompany this review. This initial brief scan proved a useful exercise because it highlighted that grey literature was a major source of information about the topic, with this being supported by peer reviewed papers. Thus, subsequent searches began with a grey literature/google/google scholar search and then accessed the academic literature which supported guidelines, recommendations and any educational programmes in existence. The output of the initial scan identified the following number of papers:

Table 2. Number of papers identified

General reviews of qualitative and quantitative research	7
General EoL literature/Health related quality of life	26
Instruments, assessments, measures, evaluations	7
Resources, interventions, guidelines & treatments	6
Diabetes specific papers	2 [1]
COPD specific papers	6 [2]
Total papers	54
Grey literature	Numerous[3]
Internet sites	Numerous

Although this initial scan was broad, some clear issues emerged and these are briefly described below. Following further discussions with the MHMC project team the scan was expanded further.

1.1 Findings

A brief overview of the findings are below.

1.1.1 Preparedness for caring

Preparedness is a term used to assess how ready family caregivers feel they are for the tasks and demands in the caregiving role. A study with 125 family caregivers of patients with life-threatening illness, found that feeling prepared was significantly associated with higher levels of hope and reward and lower anxiety levels. Psycho-educational interventions should, therefore, be designed with the aim of increasing family

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[1] *Retained for the Diabetes specific EBS*
[2] *Retained for the COPD specific EBS*
[3] *These are be expanded upon throughout this review*

caregivers preparedness to care, including practical care, communication and emotional support (Henriksson and Arestedt 2013). Because diseases are detected earlier and aggressive treatment protocols and outpatient on-going care is in place, there are longer survival times for many serious illnesses. Over years, family caregivers have assumed responsibilities that were once traditionally performed by health care professionals (HCPs) and now perform a wide range of roles which support the entire disease trajectory (Glajchen and Israel 2011). In order to help people prepare for this role, they need to be identified as such by primary and secondary care HCPs. This is key to improving support for them and to enable them to support the patient, (Carduff, Finucane et al. 2014). Many individuals have no experience of being a carer and the implications of this (Hudson, Zordan et al. 2011).

Across Europe, general practitioners (GPs) are seeing the extent of physical, emotional and financial overburden among family caring for people at the EoL (Pivodic, Van den Block et al. 2014). Carers need to prepare for their role, this involves developing their knowledge, confidence and competence. Their role needs to be valued, recognized (Keesing, Rosenwax et al. 2011) and facilitated to emphasise the positive aspects and rewards of caregiving, focusing on individual strengths and resources (Henriksson and Arestedt 2013). Being prepared can offer rewards for caregiving in that carers can feel competent and confident to take care of the patient, and take pride in handling a stressful situation in a satisfying way (Henriksson and Arestedt 2013).

1.1.2 Carer quality of life

Being prepared for caring can protect carers' well-being and many papers were concerned with the health related quality of life of carers. Approximately 10% of the UK population have an unpaid caring role for a family member or friend and make a significant contribution to supporting patients at the end of their life. Because many do not self-identify and/or are unidentified by HCPs, they are unsupported and experience poor physical and psychosocial wellbeing. Taking on the care of another person is often a gradual process, resultantly carers do not immediately identify with being a 'carer' and prefer to think of themselves in relational terms to the patient e.g. spouse, sibling, son or daughter. However as a person's condition deteriorates the caring role often became all-encompassing and carers often felt unable to look after their own needs as well as those of the cared-for person (Carduff, Finucane et al. 2014).

1.1.3 Respite for carers

Given the ageing population and the ever increasing number of people living with multiple chronic illnesses, there is an urgent need to understand what types of services are most supportive in helping to sustain caring relationships. Respite care, in its traditional sense, has not been supported as being particularly effective and there are arguments that strengthening relationships and communities, along with promoting resilience will be more helpful to carers in the long run, making the most of people's expertise rather than just temporarily relieving them of their duties. However, at the moment respite care remains the most commonly described and important carer need. There is a need to look at how respite care services can be developed, that are not just about repair, but about promoting resilience (Wolkowski, Carr et al. 2010).

1.1.4 A need for disease specific information

The nature of a person's disease brings along with it a certain trajectory which elicits caregivers' responses to this diagnosis and prognosis. Needs of carers in each individual context should be considered when targeting support or an intervention (Simonic, Furlanb et al. 2012). An integrated information giving approach addressing these domains at suitable time points should be given including written information. Health professionals can provide key information and build confidence amongst family carers so that they feel confident to request further support and advice as needed (Harrop, Byrne et al. 2014).

1.1.5 Gender and culture

In order to deliver relationship centred care to people with life limiting advanced illness this requires clinicians to take the needs of both carer and cared for into account (Wolkowski, Carr et al. 2010). Both gender and culture need to be considered (Lavela and Ather 2010) (Simonic, Furlanb et al. 2012) along with sexual orientation. Many BAME carers consider care to be 'culturally inappropriate' for them and antithetical to family relationships, thus asking for help is often viewed as stigmatising. There is concern that carers who do not define themselves as actually being a carer, in the context of BAME communities, could be at risk financially (Larkin and Milne 2013) and in other ways.

1.1.6 Main issues to address from initial scoping scan

The main issues to address arising from the initial scope and some suggested evidence based remedies and measures are described in 3 below.

Table 3. Issues to address arising from initial brief scoping scan

Issues to address	Remedies
• The conceptual confusion around key terminology, carer, care and caring, significant other etc. • Identification of carers • Levels of carers' confidence in their role • Caregiver roles • Caregiver health • Their information and support needs • Specific EoL issues • Establishing relationships between lay-carers and HCPs • Many carers are hidden patients themselves • Unrealistic expectations for them to self-care	• Feelings of preparedness, competence and reward are identified as concepts that may protect caregiver wellbeing and decrease negative outcomes • Psycho-educational/support interventions preferably to be designed aiming to increase family caregiver's preparedness to care, including practical care, communication and emotional support • Develop knowledge and competence of carers • Facilitate preparedness for caring/death/dying/ bereavement experience • Communicate, support and offer psychosocial care into bereavement • Consider and address the whole family/friends as a unit of care • Establish guidelines for conducting family meetings in the palliative care setting

• Identify family caregivers who have significant psychosocial issues • Many unable to carry on working and with normal occupations • Healthcare disparities delivery and costs of care • Future emphasis on positive aspects of caregiving and empowerment • Lack of specific education for BAME & LGBT groups	• Train palliative care practitioners in family-centered assessment techniques • Design and use family-focused psychosocial interventions during palliative care • Take into account gender and culture, and assess if additional resources are required • Couples may need to be assessed as a unit • Address preventive care for carers • Disease specific trajectories, knowledge of, implications, diagnosis and prognosis should be routinely discussed • Educational or information based resources to be developed for carers • Acknowledge an increasing emotional and physical burden of family carers towards the EoL • Design of respite care services to be not only about repair, but about promoting resilience too • Consider BAME and LGBT provision • Consider support/interventions based on the Transactional model of coping[4] • Consider the social capital of carers and patients[5] • Consider Carer Support Needs Assessment Tools (CSNAT). An evidence-based direct measure of carers' support needs in 14 domains. It is short, comprehensive and suitable for EoL care research and practice *(Ewing, Brundle et al. 2013, Ewing, Grande et al. 2013).*

1.2 Conclusions

The brief scan highlighted areas that an educational programme for carers should address, after further consultation with the MYMC project team about their interests and the proposed education programme, a more specific and expanded search was performed (please see table 4).

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[4] *Continually altering behaviour and cognitive efforts to manage internal/external demands that are appraised as exceeding individual resources. Higher levels of mastery and more positive perceptions of role = less depression and better bereavement outcome*

[5] *Social Capital frameworks provide a structure for understanding how the organisation and meaning of social contexts can potentially enhance or hinder EoL care. Research that identifies specificity in application of social capital concepts is fundamental to issues of access to services, sustaining levels of care, quality of life, and well-being. The importance of "bridged" social capital relations and networks for improved resource acquisition and information flow was identified in the literature and outlined within the palliative care social capital framework (Lewis et al. 2013).*

Section 2. General end of life care

2.1 Aims

- **To identify and appraise any educational co-designed programmes, initiatives or guidelines for carers of people at the end of their life**
- **To identify and report on any gaps in the MHMC programme**
- **To appraise any materials designed by Pennine Care NHS Foundation Trust.**

2.2 Comment

A key component of palliative care is support for family caregivers and some caregivers report positive caring experiences. However, it is important to note that this is a burdensome role and can involve physical and psychological morbidity, financial disadvantage and social isolation (Hudson and Aranda 2013).

Evidence shows that effective support for family caregivers is in a fledgling state and a research priority because there is a shortage of evidence based strategies to support family carers. There are a small number of researchers focusing specifically on family carer research in palliative care chasing limited research funding (http://centreforpallcare.org/index.php/research/ipcfcrc/). Outcomes of systematic reviews have highlighted the importance of investment in family caregiver intervention research. Without this, the field will continue to fall short of meeting standards of palliative care provision (Hudson and Aranda 2013).

One study found that only 5% of the studies reviewed addressed the measurement of clinical variables, testing either new or older measures of variables, such as anxiety, burden, depression or satisfaction and there appears to be little focus on the need for identification, development and use of common outcome measures (McGuire, Grant et al. 2012). Many reviewed studies are qualitative accounts emphasising the emotional impact of caring when other needs, such as practical skills needed to provide care, have been overlooked. Home-based palliative care services have not focussed enough on assisting carers to acquire practical nursing skills (Caress, Chalmers et al. 2009).

A Cochrane review found a low quality of evidence to show that interventions directly supporting the caregiver significantly reduce psychological outcomes or marginally improve coping skills and quality of life (such as better sleep) in the short term. There were no evaluations of coping with the caring role, quality of life, service use or adverse outcomes however. Although the authors of this review concluded that there is some evidence that supportive interventions may help reduce caregivers’ psychological distress, further research is needed to explore the benefits identified, to assess the interventions’ effects on physical health, and to explore any potential harms. Meanwhile, HCPs should enquire about the concerns of caregivers and consider that they may benefit from additional support (Candy, Jones et al. 2011).

2.3 Development of the initial scan

Following the initial scoping scan, an in depth search was carried out in order to clarify and expand upon findings and to explore education provision for this group of carers at a generic level. NHS and other relevant guidelines for carers are described to aid the development of an educational programme

As in the Paediatric Diabetes EBS, this EBS is pragmatic and uses some of the principles of ‘evidence scans’ as described by the Health Foundation (The Health Foundation 2010). This approach provides information to help those involved in improving the quality of healthcare to understand what research is available on particular topics. The purpose is to provide a synopsis of evidence to help inform discussions and to help identify if there is need for further research or development in the area covered. It can also provide a rapid collation of empirical research about a topic. Although all of the evidence is sourced and compiled systematically, this is not classed as a systematic review. That is, it does not seek to summarise theoretical literature or to explore in any depth the concepts covered by the scan or those arising from it. Elements of 'Berry picking' were also used. This is another structured method of searching which also allows for an iterative and creative searching process to take place (Barroso and Gollop 2003). In this case, the process involved:

- **Meetings and communications with stakeholders**
- **A Google grey literature search for any education programmes/initiatives (This included health provider sites and websites with a target audience of patients/carers coping with terminal illness, advanced illness and EoL issues.)**
- **An examination of related websites, reports, conference presentations and academic papers**
- **Personal communications with programme leads and researchers**
- **A library academic search**
- **An appraisal of existing programmes and initiatives**
- **An appraisal of existing materials developed by Pennine Care NHS Foundation Trust**
- **Recommendations for practice**

It is important to note that only literature written English and from between 2009-2015 has been included in the EBS, literature pri0oir to 2009 was deemed to be too out-dated for a review of this nature. Table 4, outline the extended search criteria that was used for this report.

Table 4. Search criteria

Sources	Search terms	
Carers UK	***‘end of life’* and…**	
Carers’ Trust	*‘needs’*	*‘informal caregivers’*
Health Foundation	*‘training’*	*‘spousal caregivers’*
HMIC	*‘caring’*	*‘significant others’*
Ageline	*‘care’*	*‘stress’*
Google scholar	*‘support’*	*‘burden’*
The National Institute for Health and Care Excellence (NICE) Guidelines	*‘caregiving’*	*‘needs of carers’*
The Scottish Intercollegiate Guidelines Network (SIGN)	*‘death’*	*‘education needs’*
Social Care Institute for Excellence (SCIE)	*‘dying’*	*‘knowledge’*
Sue Ryder	*‘family‘*	*‘literacy’*
Marie Curie	*‘family carers’*	*‘resources’*
Macmillan	*‘lay-carers’*	*‘services’*
Nuffield Trust	*‘palliative care’*	*‘guidelines’*
Local/regional Health Authorities	*‘hospice’*	*‘training programmes’*
System for Information on Grey Literature (SIGLE)	*‘needs (practical, physical, psychological, educational)’*	*‘materials’*
Kings Fund		*‘health technology assessment’*
Social Care online	*‘educational courses’*	*‘mhealth’*
NHS	*‘clinical support’*	*‘BME groups’*
Department of Health	*‘clinical needs’*	*‘LGBT’*
UoM Library Search	*‘life shortening illness’*	*‘relationships’*
Journals (BMC Palliative Care; BMJ Supportive & Palliative Care; Palliative & Supportive care)	*‘terminal care’*	*‘family*
	‘end of life care’	*‘health professionals*
	‘death and dying’	*‘advanced care planning’*
	‘palliative care’	*‘advanced directives’*
	‘home care’	*‘undertaking caring tasks’*
	‘family caregiver’	*‘management’*

This section of the report expands the wide range of evidence relating to caregiving for someone at EoL. Given that there is a dearth of information about carers of non-cancer patients European Association of Primary Care (EAPC 2010) this EBS considers some research and resources available relating to cancer care (Gott, Ingleton et al. 2013) where this is applicable to general EoL care (Caress, Chalmers et al.

2009), because the evidence shows that there may be some similarities between the needs of family carers of patients with advanced cancer (for example) and those with advanced nonmalignant disease (Hudson, Thomas et al. 2009). Practical needs and information of carers relating to pain control, weakness and fatigue, home care services, management of depression, management of weight loss and appetite loss could apply to many end of life conditions (Caress, Chalmers et al. 2009).

Evidence relating to carers of people at the EoL in hospices or hospitals is also included because family and lay-carers require similar kinds of psychological support to those caring at home, as transitions and interactions between formal palliative care and informal caregiving, because they could offer potentially valuable opportunities for delivering effective support and education (Gott, Ingleton et al. 2013).

2.4 Findings

Some of our findings amplified those of the initial scoping scan, identifying and preparing “carers” for their role for example is a major consideration. The original “carer quality of life” heading from the scoping scan has been expanded to include, and encompass all of the additional issues discussed below. The reluctance of many patients or carers to be identified or to self-identify as at the end of their life or as a ‘carer’ could constitute a major potential barrier to use of Trust material. Carers’ need for disease specific, such as stroke, cardio vascular, diabetes and COPD, information is important and will be addressed in supporting standalone EBSs. In addition, the need for general practice to engage with carers at an early stage and the potential use of advanced nursing doulas and/or trained volunteers has also been identified as a potential support for them.

The key areas arising from the review are discussed below:

2.4.1 Definitions and terminology

For the purposes and context of this scan there are a number of terms which require defining:

- **end of life / EoL- is used by the General Medical Council to mean where death is expected within 12 months. This definition includes people with advanced, progressive, incurable conditions.**
- **carer – there are various definitions in the literture, this review adopts the defnition outlined by NICE and adopted by the European Association for Palliative Care (EACP*) ‘carers, who may or may not be family members, are lay-people in a close supportive role who share in the illness experience of the patient and who undertake vital care work and emotion management’.* This includes both formal caring relationships and those defined as being so by patients (EAPC 2010).**

2.4.2 Identifying family caregivers

Many carers simply do not define themselves as carers, they see this is an inevitable part of life and of what is expected of them. The term ‘carer’ is often ascribed to family members or friends by HCPs whereas individuals themselves may resist being labelled ‘carers’ even though they take on the responsibilities associated with this label. Carers may not see their contribution as ‘care’, often equated with purely physical tasks, such as lifting, personal care and help with mobility. In addition it may be assumed by HCPs that there is one principal carer, whereas the reality may be that there is a network of support and care, which may include friends and other social contacts who need different information and have different support needs.

There is little information about carers of non-cancer patients and of their personal characteristics, age, gender, health, education, resources, life experience and their relationship with the patient. The difficulty for HCPs is then to discover who provides what kind of support to a patient and what each person requires in order to undertake this (EAPC 2010). Caution is suggested in terms of relying on ‘next-of-kin’ status as being sole carers of a person, although most palliative care research about caregivers relies on reports from spouses or adult children. Some recent clinical reports, have noted the assistance provided by other family members and friends. For example, a population study set over 7 years with a population of over 23,000 in Australia aimed to define just who actually provided care at EoL. Results showed that people of all ages indicated they provided ‘hands on’ care at EoL. Extended family members (not first degree relatives) and friends accounted for more than half of identified hands-on caregivers. The period of time for which care was provided was shorter for this group of caregivers however people with extended family or friends providing care were much more likely to be supported to die at home compared to having a spousal carer and it is this substantial network of caregivers who are mainly invisible to the health team who provide the majority of care. EoL services need to create specific ways of identifying and engaging these carers to ensure that they receive adequate support (Burns, Abernethy et al. 2013). The 2013 census data, when available, may reveal more about the distribution of caring responsibilities by ethnicity and other variables (Yeandle and Fry 2010). Identification of carers is particularly difficult in BAME communities where culture and tradition simply assume the caring role and this mitigates against formal identification of carers. In addition, some HCPs can underestimate the skills and abilities of carers from these groups because their English is not optimal (DH 2010).

In terms of time frames and disease trajectories, identifying people approaching the end of their life along with their potential carers, could maximise the provision of high-quality EoL planning, care and support in accordance with the person's needs and preferences. However, some patients do not wish to be identified as EoL patients and consequently, their carers are not apparent, become ‘invisible’ and become potentially uncared for. Where identification and subsequent assessment of carer need is unstructured or inconsistent it produces barriers to providing effective support for caregivers (Thomas, Hudson et al. 2010).

2.4.3 Preparing caregivers

Being unprepared for a caring role and a person's death has been associated with complicated grief[6] (Hudson, Trauer et al. 2012). The findings of this EBS indicate the importance of developing the knowledge and competence of carers; facilitating their preparedness; recognising their role; building their confidence (Harrop, Byrne et al. 2014); including them in the whole care process (Thomas, Hudson et al. 2010, Ewing, Grande et al. 2013, Gott M 2013) and treating them as an expert on the patient (NCPC 2014). HCPs interaction with households tends to focus on patient needs, so vigilance from health and social care professionals is required to address carer needs, because the two roles (patient and carer) generate different demands (Gott M 2013). For example, one challenge is the choice of place of death. A home death is considerably burdensome for carers and few studies have considered the preferences of carers regarding the place of death. Carers are less likely than patients to report a preference for home death. Often however, their preferences are not taken into account, or they may be pressured to agree with patients wishes. The current imperative to enable people to die at home may place undue moral pressure on families to provide care, whatever the cost to them (EAPC 2010).

Carers need information on signs of impending death, symptoms, implications of the symptoms, what to expect next, and instructions on what to do. This involves time and listening to carers, engendering their trust, repeating information, collaboration with other disciplines for them, and demonstrations. Content and delivery of messages can be tailored to patient and carer factors (Kehl 2015).

2.4.4 Advanced Care Planning (ACP) or Advanced Directives (AD)

An Advance Directive (AD) is a statement explaining what medical treatment an individual would not want in the future, should that individual 'lack capacity' as defined by the Mental Capacity Act. It can relate to all future treatment for example: the use of intravenous fluids and parenteral nutrition, the use of life-saving treatment (whether existing or yet to be developed) or specific procedures such as blood transfusion for a Jehovah's Witness. As a carer, it is important to be aware of the existence of an AD and where it is stored. It is also important that for it to be enforced the medical team needs to be aware of this; they could make a note on the individual's electronic or manual notes.

An AD is a valid legal document (legally binding in England and Wales) and cannot be overruled by family or carers. It is important to know that while the patient has capacity their word overrides anything contained in their AD, also the AD can be changed or revoked at any time if the patient is competent to do so. Further information about AD's is available from patient.co.uk http://www.patient.co.uk/doctor/advance-directives-living-wills.

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[6] *Complicated grief being where debilitating grief is experienced for an extended period of time. Around 10 to 20% of carers experience this.*

2.4.5 Carer vulnerability

Imbalances between carer burden and coping capacity can increase a carer's vulnerability. Carers experiencing most distress describe greater negative impacts from the loss of an intimate relationship/identity (Davidson and Gentry 2013), disease-related demands, and coping-related factors (Locock L, Robert G et al. 2014). Age is also a contributory factor with older spousal caregivers being more vulnerable, particularly when their spouse has cognitive functioning difficulties (Robinson, Pesut et al. 2012). Some patient/carer dyads just do not work and negotiating illness management, health care decisions, EoL decisions and psychosocial issues are just not tenable for the patient and carer. The greater intensity experienced in EoL caregiving, the poorer the carers self-assessed health is, with it negatively impacting on social/activity patterns and it being at a greater financial costs (Kitko, Hupcey et al. 2014). Therefore, it is imperative to assess carers in conjunction with the patient to properly address age, gender, social and cultural factors (Lavela and Ather 2010). Once identified, education and practical support can be targeted to specific groups (McNamara and Rosenwax 2010).

However, on the whole, caregivers need support throughout caring for someone at EoL, and beyond bereavement (Davidson and Gentry 2013). Pragmatism is often the driving force behind coping (Locock L 2014) with notions of 'a day at a time' appearing in many studies. Working with carers in practical ways, includes a) building up a partnership with the patient and the primary caregivers, b) identifying a set of core functions that a family/caregiver could perform; and c) obtaining a consensus on how these can be achieved (Simpson, Young et al. 2010). Research tends to focus on patient needs, but it does identify that family carers commonly see their roles as involving "an extra pair of hands", hence the provision of support and information is likely to be most effective when framed within and around their perception of the caregiving role (Palos and Hare 2011).

2.4.6 Decision Making and Managing risk

Increasing levels of decision-making for carers is often compounded by a lack of knowledge and experience, coupled with poor communication with HCPs (Davidson and Gentry 2013). For example, the management of EoL medications at home can create anxiety for carers. Although some support with medications is provided by GPs and nurses in the community, family carers primary take responsibility for storing and administering these. This can cause anxiety relating to giving correct and timely dosages, and about keeping a patient comfortable without overdosing them or risking shortening their lives. Opioids, in particular, have 'symbolic significance' in this context, the use of a syringe driver being associated with deterioration and approaching death. Barriers to managing EoL medications at home include: a) the complexity or regimens, b) unwanted responsibility in deciding when to use 'as needed' medication, c) disagreements with HCPs, and e) anxiety about making medication errors. Family carers require more information about EoL drugs and their effects and support and training in managing medication for a dying person (Payne, Turner et al. 2014).

The UK approach to improving EoL care has been the introduction of 'just in case' or 'anticipatory' medications; these have predominantly been the responsibility of nurses. Nurses have to make complex decisions when deciding when to administer these, however it is reported that the views/opinions of the patients relatives/carers are often not accounted for in this process. Carers also have concerns about distinguishing between pain and agitation, balancing risks of under and over-medication and the possibility of hastening death can cause them emotional burden (Wilson, Morbey et al. 2015).

2.4.7 Carers' use of resources

Family carers experience multiple needs for information and education, the use and needs of these resources differs according to illness, its trajectory, gender (Lavela and Ather 2010) (Nordtug, Krokstad et al. 2013) and health literacy (at what level people understand the information given to them). Work in geriatric palliative care identifies the need to recognise that there are identifiable transition points which change caregivers' abilities and need to access information and resources (Schulz 2013). It is helpful for all concerned to properly acknowledge the trajectory of illness which can result in ever changing needs for both care recipient and caregiver (Lau, Joyce et al. 2012) (Locock L 2014). In contrast to support in long-term/chronic conditions carers for those at EoL often require more specific information about how to deal with the signs of impending death (Schulz 2013). This is similar to the needs of those caring for cancer patients and relates to all aspects of the experience and stages of the illness trajectory, from diagnosis through to EoL issues (King, Brooks et al. 2014). Information should, therefore, be available in a timely, tailored way which recognises people's evolving capacity to consume, and reflect upon, what is often large amounts of unfamiliar information (Kehl 2015).

2.4.8 General Practice involvement

GPs and general practice staff are potentially a good resource for carers (Stajduhar, Funk et al. 2010). However there is a dearth of evidence associated to primary care support for carers, for example, in a recent review of colorectal cancer patients, only one paper was identified relating to the role of GP in this regard (King, Brooks et al. 2014). Marie Curie advocate that as a first step carers should contact their GP because they will need support and help, carers will also have their own health needs. Carers are likely to visit their GP more than any other support professional and, when they present, their health can then be monitored (http://www.e-lfh.org.uk/programmes/supporting-carers-in-general-practice/). There is an ongoing study, "PalliPA" which is exploring a 'best practice model' for engaging with Primary Care in the German context in their support of carers of people in care homes. It aims to improve identification and response to when support is necessary for family caregivers. Patients and their family caregiver have been enrolled onto the study in order to identify structures and evaluation tools feasible for use in practice. It is hoped that findings from this study will enable general practice teams to develop acceptable and successful strategies for the implementation of best practice to successfully support family caregivers of those patients at the end of life (Hermann, Boelter et al. 2012).

2.4.9 Doulas and Volunteers

There is some evidence about EoL Doulas[7] which, as an innovative Advanced Nursing service. Further research is advocated to ensure that the valuable contribution of volunteers in palliative care is used appropriately and effectively. A recent review found that volunteers in palliative care settings, including home settings, hospitals and nursing homes, have resulted in families being significantly more satisfied with care and with patients surviving significantly longer if they received home visits from a volunteer. However, it is important to note that of the studies reviewed, none of them examined patient and family well-being and the potential disadvantages or adverse effects of volunteer involvement (Candy, France et al. 2015).

2.4.10 Black, Asian and Minority Ethnic (BAME) care

There is a clear need for research and guidance on supporting good EoL care within different cultural traditions. Most of the existing research focuses on primary family carers in general and lacks information on the experiences of certain groups of carers, including male carers, children, new immigrants and non-host country language speakers (EAPC 2010). These hard to reach carers results in a lack of data about them and some assumption that they do not need end of life services http://lx.iriss.org.uk/sites/default/files/resources/0102104.pdf.

BAME carers are a major consideration in EoL care (McGuire, Grant et al. 2012). BAME groups hold very different views about EoL issues to those of traditional, western-based medicine and their family structures and functioning may not fit the conventional paradigm for providing traditional EoL care - one reason that BAME carers are difficult to identify (Bullock 2011). Formalising wishes in documents such as ADs are not acceptable in Chinese cultures (Clarke and Seymour 2010) and some do not even realise that they are, in fact, a carer (Scottish 2010).

2.4.11 Lesbian, Gay, Bisexual and Transsexual (LGBT)

LGBT also constitute a neglected group (McGuire, Grant et al. 2012) and a recent Macmillan review found a neglect of minority perspectives in advanced disease generally, although there is a small amount in relation to gay men and prostate cancer (King, Brooks et al. 2014). There appears to be a preference for care at home for LBGT people, partly motivated by discrimination experienced in other care services, and a high use of ADs and statements of wishes, especially where relatives disapprove of relationships. Patients talked about assumptions made by HCPs at all levels and by "peers‟ in patient and carer support groups. Some people of gay or lesbian identity did not feel that they should have to discuss their sexual orientation with HCPs and should not be placed in the difficult position of "colluding‟ with alternative assumptions made of their status. Some patients found that doctors were unwilling to regard same sex partners as primary carers and people to be consulted and supported. EoL care delivered in people's own homes should be sensitive to and accepting of all personal choices, identities and lifestyles (Harding, Epiphaniou et al. 2012).

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[7] *there is an emerging non-medical role: End of Life Doulas, individuals who help those who are dying, and their families, to feel safe and supported, as they make the transition from this life to what's next. For more information see http://www.lwdwtraining.uk/doula-training/*

2.4.12 Support from HCPs

A systematic literature review focusing on the self-reported unmet needs of home based palliative care patients and carers, found that the most frequently reported unmet need was effective communication with HCPs, the lack of which, negatively impacted on the care received by both parties. Physical care needs were met but resolution of psychosocial issues were not (Ventura, Burney et al. 2014).

HCPs, including nurses, are often unprepared for delivering EoL care (Gillan, van der Riet et al. 2014) and it may be the case that they require more intensive training in this area. HCPs have a significant role in identifying carers, assessing and meeting their needs. Some of these may need training themselves in order to identify vulnerable carers and in EoL needs generally.

Section 3. Training for carers

There have historically been national training initiatives for carers such as Learning for Living, City & Guilds, developed in 2002-2005 as part of the EU-funded ‘Action for Carers and Employment’ project led by Carers UK. Learning for Living was operating as an on-line learning resource through which carers could obtain a certificate in personal development and learning for unpaid carers, a qualification accredited at level two within the National Qualifications Framework 2. This programme is still running today (Yeandle and Starr 2007).

“Looking After Me”, a course within the department health funded Expert Patient Programme (EPP), was designed for adults looking after someone living with a long-term health condition or disability and aimed to promote self-help and the sharing of experience and expertise among carers (Hare and Newbronner 2005) cited in (Yeandle and Wigfield 2011).

There were also programmes of support for carers in Scotland - with some operating at the local level in England, mainly small projects operating through local carers’ organisations such as those linked to the Princess Royal Trust for Carers (PRTC); carer support programmes including one run by the Alzheimer’s’ Society for carers of dementia sufferers; a programme for BAME carers; and for carers in rural communities by Carers Scotland, (Carers 2009) cited in (Yeandle and Wigfield 2011).

A mapping exercise by the department of health (DoH) focusing on exploring the available training provision for carers, showed that there were at least 176 organisations providing such training in England in Spring 2006. Among these, 25% were carer organisations, 24% were local authorities, 21% were NHS bodies, and 17% were other local charities. There was also some provision available through national carer organisations and other charities (Clarke and Riley 2006).

A systematic review of UK interventions and services for carers recently reported positive findings about carer education and training programmes. Despite some evidence that skills may not be maintained over time, most studies reported consistently positive outcomes for carers in terms of developing new knowledge and skills and building confidence regarding their existing knowledge and skills (Victor 2009). A separate meta-review of international evidence on interventions supporting carers concluded that the strongest evidence of effectiveness related to education, is training and information for carers (Parker, Arksey et al. 2010).

There have been a number of education programmes, initiatives and good practice to support carers that have been identified. Many of these are from the Palliative Care Group based in Melbourne, Australia – a key resource for this subject area. Others include local and national initiatives; some are run or co-run by charities, local councils, universities, private companies and health care providers. These include group and individually based education, pilot, ongoing and completed studies.

3.1 Flag system

Throughout the following section the author has used a flag system (described in more detail below) to appraise the relevant EoL carer focussed programmes and initiatives, that have been identified as part of this EBS.

In addition recommendations in red boxes are also red flags for Pennine Care NHS Foundation Trust

☼	**VERY RELEVENT TO PENNINE CARE NHS FOUNDATION TRUST**
✡ ✡	**DENOTES VERY GOOD PRACTICE** *This could mean that the programme/guideline/initiative:* • *is established practice* • *has been nominated for an award* • *has won an award* • *is a completed successful pilot* • *is part of a larger programme* • *is the subject of a peer reviewed paper* • *meets a number of important guidelines*
✡	**DENOTES GOOD PRACTICE** Has been funded
?	**PILOT STUDY**
👥	**CO-DESIGNED INITIATIVE**
☑	**COMPLETED INITIATIVE**

♻	**ON-GOING INITIATIVE**
✦	**DENOTES THE POTENTIAL TO CONTACT**
🤝	**BAME COMPONENT**

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3.2 Caring with Confidence programme

The Caring with Confidence (CwC) programme [8] aimed to provide support to 37,000 carers in England. It was the largest programme of training for carers ever planned in the UK, with a total budget of £15.2m over three years. It was designed to provide training and support to carers, aiming to provide them with more choice and control in different aspects of their lives. Courses being around carer support and strategies to improve their health and well-being.

CwC consisted of a consortium of partners comprising four carers' organisations, led by the Expert Patients Programme (EPP) with a variety of training providers. The CwC ran for two and a half years of its intended three-years but was terminated ahead of schedule when it failed to meet targets for numbers of carers participating and because of DoH concerns about the costs of delivering the programme.

Notwithstanding this, however, CwC was well received by most carers who accessed it. Positive feedback included carers reporting beneficial impacts on their health and well-being, better access to social care support and improvements affecting those they cared for. The CwC

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[8] *CIRCLE, School of Sociology and Social Policy, University of Leeds, Leeds. LS2 9JT UK*
Tel: +44 (0)113 343 5003
Email: CIRCLEadmin@leeds.ac.uk

curriculum aims to cover practical matters, everyday life tasks, enabling carers to have a life of their own and to help carers become more confident in their caring roles, to seek formal support and explore recreational/employment opportunities.

The curriculum comprises generic and specific modules and was designed to help carers develop a range of skills relevant to their caring roles in a seven-module training course, including:

- **practical matters (such as safe lifting techniques and administering medicines)**
- **everyday life tasks (such as managing money and domestic responsibilities)**
- **being able to have ‘a life of their own’**
- **helping carers become more confident in their caring roles, to seek formal support and explore recreational/employment opportunities**

It is acknowledged by carers that the CwC programme prepared them for caring,

> *“It’s about acknowledging the carer label, realising that you are not just a wife or a parent; that you have become a carer”*
>
> *“Meeting people in similar circumstances and with a shared understanding allows you to come to terms with it”*
>
> *“CwC increased the feeling that I was a carer. It pushed me further to that point”*
>
> *“Yes, I was a carer - and it makes you think about things”*

CwC gave carers some practical skills and building relationships between carers was an important part of the programme, carer interactions became an integral part of sessions. CwC did not however, furnish carers with clinical skills. (Yeandle and Fry 2010)

The CwC programme is also available on line with self-study versions for carers.

A full evaluation of CwC has been published by Yeandle and Wigfield (2011). In addition an abridged version of this evaluation is available from appendix 1.

3.2.1 National Caring with Confidence Badged programmers

Ashford, Shepway & Swale (Kent)[9]
Carers.org - Cheshire & Warrington Carers Trust
http://www.carers.org/local-service/cheshire/services/caring-confidence-courses

CLASP The Carers Centre for carers in in Leicester, Leicestershire and Rutland.
Contact: Ranjana, Pamor, Debbie on 0116251 0999
http://www.claspthecarerscentre.org.uk/page?page=Caring%20with%20Confidence&parentNavigation=1454

Greenwich Carers Centre offer a combination of local group sessions, self study workbooks and online sessions
020 8301 8160
info@greenwichcarerscentre.org

Hampshire
http://www.cfnf.org.uk/Content/News_and_Events/News/2009/July/Caring_with_Confidence_launches_in_Hampshire.html

Scarborough & Ryedale
Stockport
Sunderland
www.signpoststockportforcarers.org.uk

Suffolk Family Carers
http://www.suffolkfamilycarers.org/index.php/howwecanhelp/search-for-events-2/icalrepeat.detail/2015/03/31/1417/-/caring-with-confidence

The Carers' Support Centre Serving Carers in North Lincolnshire
The Carers' Support Service, Working with Carers in North East Lincolnshire
(http://www.carerssupportcentre.com/

The Carers Federation – Nottingham Sessions planned for 2015

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[9] *It has not been established whether the Ashford and Greenwich programmemes are running.*

http://www.carersfederation.co.uk/services/adult-carer-support/adult-carers-nottinghamshire/training-for-carers/

3.3 End of Life training programme

The Norfolk programme has a focus on EoL care run by specialist facilitators. It supports unpaid carers of people nearing the EoL across Norfolk and Suffolk. The programme aims to address concerns and challenges faced by carers; it is funded by the Palliative Care Academy in Norfolk. Following a telephone conversation with the Executive Manager of Norfolk Carers Support, the evolution, development and structure of this course is described below.

The course began by using initial modules from CwC as a framework for discussions to involve carers in a co-design of this programme. For example, it became apparent that the bereavement/grieving process had already begun for many carers and this triggered the use of specialists in this topic, such as psychologists, to facilitate sessions. These sessions not only drew out that carers wanted effective communication with HCP's, but also that families themselves needed to communicate between their members regarding issues arising about roles and responsibilities.

Occupational therapists were present in, and contributed to, some sessions and this succeeded in bringing out still more issues about an envisaged second phase of the programme, that is, a) particular conditions, b) the deterioration of patients, and c) how this can be managed, particularly in relation to equipment for moving patients.

The complexity of some caring contexts was also identified, some caring relationships breaking down and others were conflictual. Issues about the mental health of some carers were picked up, resulting in some people being referred to appropriate services with the suggestion that carers assessments were undertaken in the context of the programme. As with the CwC programme, facilitators realised the need for carers to be in contact with people in the same situation as themselves. Building community assets is one aim of the project and this resonates with some of the good practice described in Section 6. Good practice models, with "community organisers" based in communities across Norfolk County bring used to develop the programme.

Resources are currently being developed, these will include checklists of materials and tasks a carer will need, information about arranging funerals, finance and wills, to name a few. The complete programme continues to be designed and co-designed with the local hospital, carers and its designated palliative care unit.

As with many educational programmes, attendance and promoting the uptake of the course place is a struggle. This is in part because carers do not want to leave patients. Free respite care has been offered, but at present nobody has taken up the offer. Course sessions of 3 hours are held in community centres and in the Palliative Care Centre in the James Padgett Hospital

The question of using telemedicine was also considered by this programme. There is a range of equipment which carers could use in their role and which would take some pressure from HCPs.

It is recommended that Pennine Care NHS Foundation Trust contact this organisation for more information

Contact information:

Tim Allard
Norfolk Carers Support, Connaught Hall, Station Road, Attleborough, Norfolk, NR17 2AS
Tel: 01603 219924
Email: advice@norfolkcarerssupport.org
Web: http://norfolkcarerssupport.org/

3.4 Moving and handling for carers

3.4.1 Wiltshire Council

Currently offer 4 ½ hour long courses on:

- **Handling equipment**
- **Manual handling**
- **Moving and handling**
- **Moving and people handling**
- **Advanced handling**
- **First aid for carers**
- **Food safety, Nutrition and Hydration**

These are held at various venues including memorial halls

http://carersinwiltshire.co.uk/training/

3.4.2 NHS North Valley “Moving Forth - Moving up the bed for a person who requires assistance from two carers”

NHS North Valley have produced a useful document demonstration of best practice of moving up the bed when a person requires the assistance of two carers

http://nhsforthvalley.com/wp-content/uploads/2014/02/Moving-Forth-Information-for-families-and-unpaid-carers-when-caring-for-an-individual-at-home.pdf

It is recommended that the MHMC team address the issue of moving and handling for carers. Ensuring that there is provision for training and appropriate equipment and that any recommended and/or aids are available to carers and patients as part of MHMC

3.5 Carer one-to-one education programmes

3.5.1 An educational package to support lay-carers to manage breakthrough subcutaneous injections. Development and evaluation of a service quality improvement[10]

Abstract (abridged)

Palliative care services strive to support people to live and die well in their chosen environment, with optimal symptom control and a pattern of care supportive of lay-carers. The likelihood of patients remaining at home often depends upon lay-carers, who may be required to manage subcutaneous medications. Structured education programmes for lay-carers result in positive patient and lay-carer outcomes relating to symptom management, provide lay-carers with the knowledge to understand the rationale of good symptom management and adds to their confidence in administering the right drug for the right symptom at the right time. This generates improved patient outcomes and decreases unwanted and inappropriate admissions to acute care facilities. There is some literature confirming the ability of lay-carers to successfully administer pre-prepared syringes for symptom control, but few studies concern themselves with the practice of also teaching lay-carers to prepare these injections. There is resistance from some palliative care service providers about the appropriateness of teaching lay-carers to prepare and administer subcutaneous injections in part due to the perception that the task is too burdensome for family members. In addition, there is organisational and individual uncertainty related to legal, jurisdictional and scope of practice issues for registered nurses and lay-carers.

This study reports on the development, trial and evaluation of a package that teaches lay-carers to manage subcutaneous medications used for symptom control in home-based patients. The package was developed by palliative care stakeholders and comprises an educational session, delivered by nurses, and a range of demonstrative, audio-visual and written resources. It was trialled across 24 sites and was finally evaluated

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[10] *This project was funded and supported by the Australian Government, Department of Health and Ageing under the Supporting Carers of People Requiring Palliative Care At Home projects.*

by 76 lay-carers (pre and post-use) and 53 nurses. Lay-carers and nurses rated the usefulness and relevance of the package highly – all ratings were above 5 on a 7-point scale. The study is described in table 5 below:

Table 5 Summary of the training package to support lay-carers to manage breakthrough subcutaneous injections

Background to package	Delivery of Package
The package was developed by palliative care stakeholders. It is suitable for delivery in a one-on-one format in the lay-carer's home. It can be implemented across various health and geographical settings. Different teaching materials and modalities allow for individual differences in rates and style of learning. 76 lay-carers and 26 nurses highly rated the usefulness and relevance of the package.	An education session delivered by nurses with a range of demonstrative, audio-visual and written resources that educated and supported lay-carers to competently and safely: • **prepare, store and administer subcutaneous injections** • **to monitor subcutaneous sites** • **to manage a medication administration record suitable for easy assessment by health professionals** • **to understand the uses of common medications used in palliative care.** The education session required between 20 and 60 minutes to complete and was used to introduce the suite of 8 resources developed for the study. The session included: Standardised information content, focusing on safety, competency and skills (inclusive of preparation, storage and administration of breakthrough injections) and deliverable by registered nurses to lay-carers. A training manual was developed to guide clinically registered nurses in the delivery of the education session. A suite of resources was developed for use within the education session and to provide lay-carers ongoing support in their day-to-day management of subcutaneous medications. All the materials produced by this study can be accessed via: http://www.caresearch.com.au/caresearch/tabid/2145/Default.aspx

3.5.1a Feedback on the package

Lay-carers perceived the overall usefulness of the package as soon as they had completed their one-on-one education session. This perception was maintained after they had had the experience of symptom management using subcutaneous medications. They were satisfied that the package information was relevant to them and the content provided necessary technical skills to manage subcutaneous medications. Importantly, they felt confident that they could safely pre-prepare and inject subcutaneous medications. In addition, the package decreased their stresses surrounding subcutaneous injections, and they were satisfied that they could assist with symptom management. The package, by allowing access to standardised and relevant information, empowers lay-carers to care safely for loved ones at home.

Nurses rated the education session highly for aspects such as appropriateness to the needs of lay-carers, providing the necessary information to allow lay-carers to safely pre-prepare and administer subcutaneous injections. Similarly, they indicated that the issues relevant to subcutaneous injections of palliative care medications had been well explained and the components of the package provided useful resources for lay-carers.

Nurses felt that the education session was easy to deliver, adequately explained injecting issues and recommended its continued use. Notwithstanding this, delivery of the standardised education challenged some nurses, possibly because it encompassed practice change. Clinical opinion varied as to the appropriate time in the patient's palliative care trajectory to present the education session. The consensus was that the time for package introduction depended upon each particular clinical situation and lay-carer. Some commented on the clinical load imposed due to the time required to deliver the session depending upon the clinician and individual lay-carers' abilities and learning styles. They concurred however, that with continued experience in education delivery, the time required to introduce the package would decrease.

Nursing opinion was divided concerning whether it is safe and appropriate for lay-carers to manage subcutaneous injections. Some nurses reiterated their concerns about safety issues related to lay-carers managing symptoms and the burdensomeness of that task. However, given lay-carers high level of satisfaction with the package, it may be that nurses, and other health-care professionals, have been overprotective or gatekeeping in their attitudes to lay-carers.

The package showed that lay-carers can learn to manage subcutaneous injections, thus contributing to breakthrough symptom control in a timely and effective way. It is likely that use of the package can contribute to more patients being able to die in the environment of their choice, their home. Potentially, this will result in an improved quality of death and decrease the cost burden to the health-care system incurred when distressed patients are unnecessarily transferred to acute care facilities. If the ability of lay-carers to provide symptom management is improved by initiatives such as the package described here, then the capacity of professional palliative care staff, particularly nurses, to care for more people will be enhanced.

3.5.1b Safe practice measures[11]

The issue of safe practice was a fundamental consideration throughout the package development. To reinforce written medication information, a colour coding system, adapted from anaesthetic drugs safety standards and advocated by an Australian national labelling project, helped lay-carers to identify correct medications, and avoid errors, through the use of labelling pre-prepared syringes. The importance of the colour coding system was emphasised during the education session. Lay-carers were taught that they could use the coloured labels on the pre-prepared syringes as a cue to help distinguish between medications, even when they were tired or distressed. All the pre-prepared injections were stored in secure containers in the refrigerator. The fridge door magnet incorporated the colour-coding system, thus further consolidating the colour prompt for the lay-carer. The magnets were designed to be written on, so changes in medication could be easily updated by nurses or lay-carers. The colour coding system was uniform across all package resources including the medication booklet and DVD.

Another safe practice measure was the diary provided to lay-carers that encouraged the recording of every injection given as well as the effectiveness of the medication for symptom relief. This clinical tool proved to be of great value to both lay-carers and visiting health professionals. Lay-carers experiencing a sense of security in having a record of injection administration as pressures associated with the caring role often led to an inability to accurately recollect medical detail. Indeed, most lay-carers chose to continue using the diary even after study completion. Nurses reported that they could easily interpret the information contained within the standard diary and this helped them monitor medication effectiveness, progress of symptom evolution and patient condition.

3.5.1c Conclusion

This study demonstrated that if lay-carers are supported with education and resources, tailored to their needs, they can confidently, safely and competently manage breakthrough subcutaneous medications to relieve symptoms in home-based palliative care patients[12] (Healy, Israel et al. 2013).

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[11] *Legislative requirements - To clarify issues about the legal, jurisdictional, and scope of practice issues, related to the common palliative care practice of preparing subcutaneous injections and leaving them in the home for subsequent administration by lay-carers, the Brisbane South Palliative Care Collaborative prepared a document entitled Guidelines for the Handling of Medication in Community-Based Palliative Care Services in Queensland. This document has been endorsed by Queensland Health, Australia and complies with the Health (Drug and Poisons) Regulation 1996, the Queensland Powers of Attorney Act 19982, and the Guardianship and Administration Act 2000.*

[12] *Findings may not be directly applicable across all palliative care service populations. And this study is not applicable across countries due to differences in legal codes.*

3.5.2 Reducing psychological distress of family caregivers at home based palliative care patients. Short term effects from a Randomised Controlled Trial (RCT).

✡ ✡

Background:
Palliative care is expected to incorporate comprehensive support for family caregivers given that many caregivers suffer psychological morbidity. However, systematically implemented evidence-based psychological support initiatives are lacking.

Aim:
The objective of this study was to prepare caregivers for the role of supporting a patient with advanced cancer receiving home-based palliative care by offering a one-to-one psycho-educational intervention. We hypothesised that primary family caregivers who participated in the intervention would report decreased psychological distress (primary outcome), fewer unmet needs and increased levels of perceived preparedness, competence and positive emotions.

Methods:
A three-arm RCT was conducted comparing two versions of the intervention (one face-to-face visit versus two visits) plus standard care to a control group (standard care) across four sites in Australia.

Results:
A total of 298 participants were recruited; 148 were in the Control condition, 57 in Intervention 1 (one visit) and 93 in Intervention 2 (two visits). Relative to participants in the control group; the psychological well-being of participants in the intervention condition was improved by a small amount but non-significantly. No significant reduction in unmet needs or improvements in positive aspects of caregiving amongst the intervention group were identified. However, the intervention demonstrated significant improvements in participants' levels of preparedness and competence for intervention 2.

Conclusions and implications:
This research adds to an body of evidence demonstrating that relatively short psycho-educational interventions can enable family caregivers to feel more prepared and competent in the role of supporting a dying relative (Hudson, Trauer et al. 2013).

The conceptual framework for guiding the intervention was based on one identified in the original scoping scan, that of a transactional model of stress and coping, continually altering behaviour and cognitive efforts to manage internal/external demands that are appraised as exceeding individual resources. Higher levels of mastery and more positive perceptions of role result in less depression and a better bereavement outcome.

This psycho-educational focus included tailored information and resources given to family caregivers to promote psychological well-being by preparing them for their role. Each caregiver was allocated a Family Caregiver Support Nurse (FCSN) who assisted the local palliative care service to assess caregiver needs, establish a care plan and provide additional caregiver support. The FCSNs received training from the research team and an intervention manual was developed to foster consistency in delivery. The intervention is described in table 6 below and it was tailored according to location, this is rural participants received more phone contacts.

Table 6 Design of the intervention

Step 1	Preparing carers for the intervention. The FCSN (i) phoned family caregivers within 3 days of randomisation to advise them of the FCSN role; (ii) sent them the family caregiver guidebook; (iii) provided written information about the FCSN/the intervention; and (iv) arranged a home visit within 1 week.
Step 2	Involved assessing caregiver needs and preparing a care plan. Home visit was carried out by the FCSN who (i) assessed unmet needs; (ii) developed a care plan in conjunction with the caregiver (and the patient, where pertinent) and the local palliative care team; and (iii) prepared the caregivers for their role by explaining educational resources.
Step 3	Involved re-assessing needs and evaluating the care plan: The FCSN reviewed caregivers' status and evaluated the care plan by phone. Caregivers were reminded about relevant resources and strategies to promote psychological well-being, including trying to identify positive aspects of caring.
Step 4	Involved assisting the family caregiver to prepare for their relative's death and to prepare for bereavement. Home visit by the FCSN was carried out to focus on preparing caregiver for aspects typically associated with imminent death. Caregivers were also advised of common reactions during bereavement and of available bereavement resources. The FCSN concluded the structured component of the intervention with a summary (including written format) of key strategies and resources. The care plan was revised, incorporating referral to other services as required.

Although this intervention appeared to increase family carers' sense of preparedness and competence for their role: - There was no significant decrease in psychological distress, a lessening of unmet needs or more positive perceptions of the carer role

- People who received more personal visits fared better overall
- There was an apparent absence of negative sequelae for caregivers in the intervention group
- A large proportion of eligible caregivers declined to participate and many did not complete the intervention
- It can never be certain whether interventions are carried out the same by all deliverers
- It is recommended that interventions are targeted according to specific people's needs

3.5.3 For physical and personal care skills. Improving care-giver confidence in their ability to look after patients using focused

Exert from the abstract

Objectives:

- To increase carer confidence in looking after patients at home
- To facilitate patients and carers to achieve goals that are realistic and that they have chosen for themselves
- To use qualitative and quantitative outcome measures to assess the feasibility and usefulness of this intervention as part of an ongoing service

Background:

Carers are rarely taught the practical skills they need to be able to provide physical and personal care. This can make them feel insecure and can lead to the patient feeling as though they are a burden. This pilot study aims to see whether training carers can empower them to be able to carry out these tasks with increased confidence.

Intervention:

The intervention will be structured around contacts between the carer and an Occupational Therapist (OT). The OT will visit the patient and carer at home and discuss goals they wish to achieve (e.g. on helping a weak person on and off the toilet/helping an unsteady patient get into the garden safely, etc) and the OT will give the patient and carer realistic options of how these may be achieved. The carer will then receive training to help obtain these goals. A follow up visit will involve additional training of the carer to consolidate skills within 2 weeks of the first visit.

This study aims to develop a personalised educational intervention for lay-carers to learn the practical skills they need to look after patients with palliative care needs in their home. The information obtained from this study *(outlined on the previous page)* will be used as evidence to support an ongoing service at Sobell Hospice Charity for the training of carers. It is hoped that the results of this study will help to guide how this is best undertaken.

A study with Oxford University and Sobell Hospice Charity

http://www.sobellhospicecharity.org.uk/node/524

Contact:

Bee Wee
bee.wee@ouh.nhs.uk

http://www.hra.nhs.uk/news/research-summaries/individualised-informal-caregiver-training-for-palliative-care-at-home/#sthash.jY88upQB.dpuf

3.6 Carer group education programmes (CGEP)

3.6.2 Teaching family carers about home-based palliative care: final results from a group education programme

✡ ✡

Without the considerable support provided by family carers, many patients receiving palliative care would be unable to remain at home. However, family carers typically lack the required information and skills to prepare them for such a role. Pilot work has demonstrated that group education programmes for family carers can be readily developed; they are feasible, accessible, and useful. This project sought to build on pilot research further by evaluating the outcomes with a larger number of participants.

The programme aimed to prepare 96 primary family carers for the role of supporting a relative with advanced, non-curative cancer at home. The psycho-educational programme[13] was conducted at six home-based palliative care services across metropolitan and regional Victoria, Australia.

This study demonstrated that a group education programme to prepare family carers for the role of supporting a dying relative at home was effective. Findings also indicated that, not only is it possible to prepare family carers for their role, it is also possible to help them develop and recognise positive aspects of their role[14]. A description of the programme is below.

Table 7 Description of a group education programme

Aims and Measures taken	Format of training
Aims To examine the effectiveness of a group education with 96 participants. **Measures** Carer competence, preparedness, rewards, and information needs x 3 time points:	The psycho-educational programme consisted of: • **3 consecutive weekly sessions** • **1.5 hours in duration presented in a group format** The CGEP was designed for a minimum of four and maximum of eight carers and focused on:

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[13] *The main content of the Carer Group Education Programme (CGEP) was adapted from an earlier psycho-educational intervention with individual home-based family carers.*
[14] *NB. There was no control group to compare findings with however.*

1) at the beginning of the programme 2) at the completion of the programme 3) two weeks later **Findings** 96 participants completed all three time periods. Between Time 1 and Time 2, the intervention had a statistically significant positive effect on preparedness, competence, rewards, and having informational needs met. These outcomes were maintained at Time 3. Participants also reported additional benefits; • being more informed about services • feeling more supported • being more prepared	**1) the typical role of a carer in the palliative care context, including an overview of the services available from the palliative care team, local doctor, and other support services** **2) strategies for self-care (carer wellbeing) and for their relative/friend (e.g., symptom management)** **3) strategies for caring for a person when death is approaching, and overview of bereavement supports for the family carer** Delivered by HCPs (e.g. social workers, nurses) following a short training session. The education sessions were semi structured and included a mix of presentation and group work. Carers received a copy of a Carer Guidebook designed specifically for preparing family carers for the role of supporting a dying relative. Handbook: **Supporting a person who needs palliative care: A guide for family and friends** http://centreforpallcare.org/assets/uploads/PCV%20Supporting%20a%20person%20PC%20guide%202012.pdf centreforpallcare@svhm.org.au

Given that there was a high refusal rate for this programme, it is necessary that the MHMC team explore strategies for enhancing uptake and obtaining enough participants to make programmes viable. It would be useful to outline specific barriers to attending programmes and then investigate strategies to address them. Time was the main obstacle to attending the programme. It may be that a shorter version of programmes could be offered or, alternatively, a multimedia version of the programme could be developed for carers to watch at a convenient time. Many carers who work full-time would have preferred an evening time, so services delivering the programme may need to consider a variety of times or locations to maximise carer attendance. (Hudson, Thomas et al. 2009)

3.7 Information Communication Technology (ICT) and Telecare

The potential of information communication technology (ICT) in having a major role in supporting the provision of domiciliary care in England is the subject of an exploratory review carried out by CIRCLE[15]. This report explored the potential of ICT initiatives to support and engage carers and care workers (including BAME groups) in the context of supporting the provision of long-term care at home, paying particular attention to informal carers and immigrant care workers in Germany, Spain and the UK.

Research on the use of ICT equipment is still at a relatively early (and inconclusive) stage of development although expanding rapidly. Evaluation is required on the impact of telecare and ICT interventions. Robust studies will explore impacts and benefits, examine the limitations of potential solutions and propose practical guides to implementation (including legal, ethical, organisational, clinical and technical components).

There are a number of issues relating to developing ICT and telecare services. Potentially, these have a valuable role to play as a component of future care packages in the case of older people generally and in EoL care particularly. For example, ‘trigger factors’ traditionally associated with older people (falls, failure to take medication, etc.) could be assisted, prevented or minimised. People can be receptive to the use of telecare equipment because they want to remain in their own homes and prefer this to residential or day care. Carers have mixed opinions on telecare equipment, some finding it reduced their anxiety, giving them more recreational and occupational freedom in their everyday lives, others expressed concerns about the potentially ‘de-humanising’ aspect of these services, and were concerned about their costs, ease of use and clinical support available.

Telemonitoring projects can liberate GPs, who had formerly needed to visit older patients to conduct monitoring procedures. GPs found they could delegate these responsibilities to nurses by a system of service user reports conducted by telephone, resulted in time and travel savings. The implementation of home-monitoring can significantly save nurses travelling time, particularly in rural areas and can improve patient condition and there is a positive impact on education and social support for users of ICT-based equipment.

For carers living with an older person with a chronic condition, the report found that ICT equipment in place did not directly reduce carer stress and mental health problems. However, it did increase social contacts, increased support and less need for information about the illness. Additional contact with other carers and family, facilitated by the ICT equipment, was also regarded as valuable by carers. ICT based initiatives lead to carers feeling better informed and more ‘empowered’ by the improved access to information made possible by these schemes. Other

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[15] *The Centre for International Research on Care, Labour and Equalities, University of Leeds, UK and the same organisation that evaluated the Caring with Confidence programmeme.*

studies have found that ICT-based interventions can result in reduced carer stress and depression, although the effects reported varied for different groups of carers and baseline levels of 'burden'. More empirical evidence needs to be gained from patients, carers and professionals. Examples of the potential of ICT based initiatives to support carers are outlined in this sub-section (Yeandle and Fry 2010).

A range of ICT-services are currently being used throughout Europe, including telecare, online support groups, online training and monitoring systems and is increasing as a tool to support family carers of older people. The key characteristic of ICT is its ability to provide the help needed, when it is needed thus flexible and important in the consideration of future needs for carers because it can improve their quality of life in a number of ways (Blusi, Asplund et al. 2013).

3.7.1 Online course: 'Certificate in Personal Development and Learning for Unpaid Carers'. City and Guilds – 'Learning for Living'

As mentioned above, "Learning For Living" is an internet-based training course designed to provide carers with the skills and knowledge they need in their everyday caring roles. Successful completion of this course results in a formal qualification which may be useful for some. Carers with access to a computer can access online resources at www.learning-for-living.co.uk. The four study modules are:

1. **Moving forward: involves help on returning to study, coping with complexity in life and planning for the future.**
2. **Taking care: involves keeping healthy and enjoying life.**
3. **Living with others: involves understanding relationships and coping with loss.**
4. **Managing as a carer: involves money management, safety matters and understanding care services.**

The modules are delivered via a range of online tests and quizzes, involving typing in appropriate answers and completing drop-down multiple-choice questions. There are also useful DVD-style video and audio recordings to help carers with the course. Tutors are available via email to provide instruction and feedback. There is also a helpline linked to the course for technical assistance.

The course is funded and delivered by affiliate organisations such as local authorities and colleges. These organisations recruit carers to the course and offer a face-to-face introductory session to help carers who may lack appropriate IT skills. This course generally relies on a suitable 'champion' on its behalf and a shortage of funding for carers often renders it difficult to roll out the course in, as an ambitious manner, as would be preferred.

Since 2004, however, approximately 700 carers have engaged in the course. Future plans involve updating it to cover more recent carer policy developments such as Direct Payments. City and Guilds has not developed any courses or facilities to specifically address BAME carers and care workers, although diversity issues are well integrated in its existing courses (Yeandle and Fry 2010).

3.7.2 ACTION (Assisting Carers using Telematics Interventions to meet Older peoples' Needs)

A range of ICT-services are currently being used throughout Europe, including telecare, online support groups, online training and monitoring systems and is increasing as a tool to support family carers of older people. The key characteristic of ICT is its ability to provide the help needed, when it is needed thus flexible and important in the consideration of future needs for carers because it can improve their quality of life in a number of ways. ACTION is a support system that offers a combination of multimedia programmes and videophone. It was developed in collaboration between six European countries, aiming to support frail older people and their carers in their own homes, via ICT.

> *"If I worry, or something suddenly happens, I push a button and another person comes into my living room. It is such a security. Otherwise it takes them an hour to get here".*

The intervention consisted of a modified version of the ACTION-service which research has shown to be both user-friendly and beneficial. ACTION is a support system that offers a combination of multimedia programmes and videophone. It was developed in collaboration between six European countries, aiming to support frail older people and their carers in their own homes, via ICT. The intervention comprised information and educational programmes covering themes such as a) caring in daily life, b) incontinence, c) dementia[16], d) stroke, e) pressure sores, f) EoL care and emergency situations, g) coping, h) planning, i) respite care, j) claims, and k) benefits. Participants were provided with a computer with Internet access, information and educational software, webcam, and access to a secure social community with other family carers as well as call centres. The technical equipment was given to the family carers through each local authority at no cost to the carer. The purpose of the internet-based secure social community was to enable safe and easily accessible contact with peer family carers as well as encouraging them to contact the call centre via internet and webcam. Each municipality had a call centre with professional support nurses. The call centres were located within existing municipal support service offices for family carers and were accessible during office hours. Prior to the start of the intervention, family carers were educated in using the technology. Training and education was given by support nurses in the family carers' homes.

They found that access to Internet and web camera contributed to reducing loneliness and isolation, strengthening relationships with relatives living far away and enabled access to services no longer available in the area. Use of the ICT-service had a positive influence on the relationship between the older carer and adult grandchildren. It also contributed to carer competence and promote feelings of regaining independence and a societal role. In order to fully experience the benefits, family carers need to be frequent users of the provided support.

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[16] *Many of the carers involved in this intervention were dealing with dementia.*

Adequate training and encouragement from others were essential in motivating family carers to use the support service. Participants found that it helped them in adopting new technology with help from others and they regained social inclusion.

Appraisal of the study by the authors

There is not the same intensity in group meetings or in personal contact with support staff. Participants found the intervention improved their lives enormously however, and were inventive in their use of this technology. Some used it for banking and shopping, others were encouraged by their children and, especially, grandchildren, to use it and keep in regular contact. They recaptured their position in society and reduced loneliness making new E-acquaintances and resuming leisure activities (even if this was only reading a book while their spouse used the technology!). They accessed peer carer support and attended health seminars and other web resources. Personal development, self-esteem increased as people were acknowledged as competent carers. They had easy access to professional help. Relationships with cared for spouses also strengthened as the spouses also used the technology for their own benefit. Although this study was set in Sweden where rural carers are extremely isolated ICT-based support services have the potential to make support to family carers in other contexts (such as not wanting to leave a dying relative) since it can be provided and accessed regardless of geographic distances (Blusi, Asplund et al. 2013).

3.7.3 Tunstall - telecare solutions manufacturer and supplier

Established in 1957, Tunstall considers itself to be “the world’s leading provider of telecare and telehealth solutions.” Based in the north of England, the company operates in 30 countries, supporting 2.5 million people through the world by:

- **developing world leading telecare technology**
- **offering support, via a network of 160 engineers nationwide (UK), backed up by a 24-hour customer satisfaction centre**
- **investing in research and development and**
- providing certified facilities

Tunstall is a founder member of the Continua Health Alliance[17] and manufactures a wide variety of telecare / telehealth solutions, such as:

- **Telecare home units**
- **Telecare sensors**
- **Telehealth solutions**

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[17] *A non-profit, open industry alliance of the finest healthcare and technology companies in the world, whose members have joined together to improve the quality of personal healthcare*

- **Telehealth monitoring software**
- **Activities of daily living solutions**
- **Environmental control solutions**
- **Mobile alarms**
- **Telecare home unit accessories/packages**
- **Accessories for telecare**

Tunstall's website offers a range of customer support facilities including advice on dementia, falls, intermediate care and learning disabilities, as well as telecare solutions for each condition based on the available equipment. There are also video and audio interview-based case studies available to download. It's website also hosts a Telehealthcare Support Group which has dedicated web pages available to customers via a log-in system.

A series of regular "webinars" have been designed (Internet/telephone based seminars) that allow customers to listen to a presentation and then engage in a Question and Answer session at the end.

A Telehealth Online Resource Centre was recently launched via its website, designed to offer to telehealth customers (including carers) resources such as case studies, information on installation of equipment, details concerning engineer support, downloadable instruction booklets and return procedures.

For professionals, there is also a password-enabled online Telecare Training Tool that allows care workers to engage with a number of virtual care assessment scenarios and to participate in role-playing as a way of gaining knowledge, experience and confidence in prescribing the kind of telecare packages that would be suitable for a client in each case[18].

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[18] *Tunstall is currently providing technology and eqipment in the three Whole Systems Demonstrator (WSD) trials, whch aim to find out if integrating health and social care using new technology can help people well at home. The demonstrator sites aim to provide information about 'the extent to which integrated health and social care supported by appropriate technologies can promote individuals long terms well-being and independence, improve quality of life for them and their carers, improve the working lives of health and social care professional.'*

3.7.4 Nottingham City Council's telecare project[19]

This telecare project is one of a number of examples of what local authorities in the UK offer carers in the form of ICT-based initiatives. A range of telecare sensors is available to people over the age of 65 and to disabled people aged 18+ who have been judged, in a community care assessment conducted by a social worker, occupational therapist or home care worker, to have suitable support needs. The installation of sensors etc, is free of charge, although a small weekly charge is made to cover monitoring costs. This project has been developed using funds available from the Preventative Technology Grant as well as resources from some other local authority budgets. It is promoted in the region via a) carers events, b) day care centres, c) local media, d) council newsletters, e) a short video, f) display stands at libraries, h) the Internet, i) GP and health surgeries, and j) via social care staff. Immigrant and ethnic minority carers have been targeted via literature translated into relevant languages. Although no formal evaluation of the project has been conducted, anecdotal feedback from carers is reported as 'very positive'. Staff also view telecare as an important part of present and future healthcare packages, although they emphasised that telecare was not regarded as a replacement for more traditional 'face to face' care services.

For its own social healthcare staff, Nottingham County Council makes extensive use of Tunstall's online training tool to enable them to learn how to assess carers' ICT needs effectively. In-house training is also offered, including guidance on how to use a computer-based intranet system as a source of information with newsletters, frequently-asked-question lists and blogs by other members of staff (regarded locally as a good way of sharing experience).

One barrier to effective use of these technologies is a lack of co-ordination between the different IT systems used in social care and health. The local authority has been considering harmonising these systems to enable all staff to access the same information. It was also noted that some members of staff have been reluctant to use IT equipment, because they lack knowledge and confidence. To address this, refresher training is advocated.

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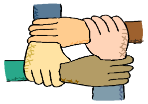
[19] *This initiative is pump-primed by the Department of Health's Preventive Technology Grant.*

3.8 Education aimed BAME communities

3.8.1 National Black Carers and Carers Workers Network (NBCCWN)



The National Black Carers and Carers Workers Network (NBCCWN) is facilitated by the Afiya Trust, whose purpose is to work towards reducing inequalities in health for racialised groups in the UK. The Afiya Trust, established in 1997, hosts this website and is the umbrella network through which the Afiya Trust organises its carer activities. NBCCWN's regional and London networks represent organisations in both the voluntary and statutory sectors and holds regional meetings and organises events for Black carers. There are contact details on the web page for the Carer Network Co-ordinator and links to related publications supporting black carers and those who work with them[20]. Among the issues related to telecare developments are the following:

- **People from different communities require culturally sensitive ways of accessing the services they require, and some services may need to adapt the way their services are provided appropriately.**
- **Services for IEM communities are often set up on a time-limited project basis and are not always properly evaluated. As a result these projects are often vulnerable when funding ends. Such projects need to be planned with a view to mainstreaming.**
- **It is important that services target hard to reach communities and that they are properly monitored. If services can be demonstrated to provide improved health, they are more likely to be sustainable.**

There will always be carers with BAME backgrounds who lack knowledge and skills relating to ICT. There are also major barriers to overcome relating to different languages. However NBCCWN are receptive to advice and guidance on how ICT and related technologies might help support and engage carers linked to the organisation should funding be available to prioritise this work (Yeandle and Fry 2010).

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[20] *Beyond We Care Too, Putting Black Carers in the Picture" (2008). http://www.southglos.gov.uk/Documents/beyond_we_care_too.pdf*

Section 4. Existing written resources for carers

Carers have said that access to information is vital in helping them manage the impact of caring on their lives. We need to develop a better understanding of how different segments of the population of patients at the end of their life and their carers understand and make use of information relevant to their circumstances. This includes looking at such factors as age, gender, ethnicity and education level in relation to different communication media and contexts. In addition to web resources being downloadable, some carers may prefer a physical booklet for aspects of care (King, Brooks et al. 2014). The following sub-sections describe and appraise some of the written information that is available.

4.1 What to expect when someone important to you is dying. A guide for carers, families and friends of dying people

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Resource:
http://www.ncpc.org.uk/sites/default/files/What_to_Expect_FINAL_WEB.pdf

Contact info:
Sue Ryder, Hospice UK, NCPC
Published March 2015
ISBN: 978-1-910286-04-3

Appraisal:
This document is excellent and clearly maps out the dying process for lay people in a sensitive manner and in a very accessible format. It poses and answers questions lay-carers may ask. In addition, there are some pages giving more formal advice on the whole process and end of life trajectory. Altogether a very good resource.

4.2 MACMILLAN: Hello, and how are you?

Resource:
This is a guide for carers, developed by carers

http://be.Macmillan.org.uk/Downloads/MAC5767HelloAndHowAreYou.pdf

Summary:
The McMillan Expert Patient Group provides tips for carers on different areas of care and self-care after a diagnosis of cancer has been made, and rather than providing information to the carer, mainly refers him/her to sources of help/information. The handbook contains links/information which are out of date, for instance it mentions the Liverpool care pathway and provides a link no longer valid to the online CWC programme.

The handbook is organised in 12 sections. Sections 1 to 9 covering topics from basic information, the role of the carer in the current system of health and social care, emotional issues, legal matters and coming to an end of the caring role (the EoL care and support is mainly only referred to in Section 7).

Sections 10 to 12 provide a good directory of services and organisations that offer support to the patient and carer.

Appraisal:
The language used throughout the handbook is simple and easy to read, with no use of jargon or medical terms. With 120 pages this handbook could be overwhelming to a carer - their wide ranging “responsibilities” being presented to them throughout. This would be more useful used as a reference book to refer to as a carers journey reaches different stages described, e.g. coming to terms with the diagnosis, practicalities, self-caring, advance care planning and bereavement. The handbook could have benefited from sharing anonymised examples of situations that new carers need to be alert to in order to realise of the relevance and importance of following some of the tips provided. It could also benefit from being more specific, e.g. urging carers to have all the information needed after a hospital discharge but failing to say exactly what this information should consist of.

4.3 Supporting a person who needs palliative care: A guide for family and friends

Resource:

This is a freely available resource, which can be accessed via:

http://www.centreforpallcare.org/assets/uploads/PCV%20Supporting%20a%20person%20PC%20guide%202012.pdf

Appraisal:

This 84 page booklet would be invaluable for carers unless they had reading difficulties and/or English was not their first language. It can be dipped into according to need and covers the whole caring process, from the identification of carer status, to the death of the patient. Being an Australian production, it also addressed BAME issues. This would be a resource worth purchasing by Pennine Care NHS Foundation Trust, to be used as part of the MHMC programme.

It was developed using an evidence multi-disciplinary base and co-designed with carers. The use of the guidebook has also been evaluated in several research studies as part of a broader strategy aimed at enhancing family carer support. Although the original edition was aimed at carers of adults with cancer being cared for at home, most of the content remains relevant for people in a variety of settings and for those who are confronted by other life threatening illnesses.

This new edition includes updated information about these broader contexts for palliative care, including those in aged care homes (also known in Australia as aged care facilities).

The chapters are as follows and are detailed below for information:

- Being a family carer: what's it all about?
- Caring for yourself and your relationships
- Caring for your relative at home
- Practical care
- Caring for your relative in hospital, hospice or aged care home
- Advance care planning, legal issues and funerals
- Care as death approaches and bereavement
- What resources are available?

Section 5. Existing web resources

Web sources of good quality information for carers are often collated and organised by charities or organisations representing the interests of particular groups e.g. symptom-oriented or disease-oriented organisations. However, despite having a specific focus most sites provide ‘general’ information about caring or links to further information collected elsewhere.

Some of the best quality online resources are produced by the major cancer charities that have developed material focusing on the needs of both patients and carers. One of the reasons for the wider applicability of the cancer-based sites is that cancers can occur in many locations in the human body and thus result in a wide variety of symptoms. The sites therefore include material developed in cancer care but which is often highly relevant to caregiving in other illnesses and are helpful in signposting carers to useful information. Other sites/organisations are not only concerned with symptoms which manifest at EoL, but with the whole process of dying in psychological, practical and philosophical contexts. Although a number of resources had specific links to alternative formats and languages, maximising accessibility to non-English speakers, those for who English is a second language and those who use alternative language formats because of disability should be a key consideration in developing the MHMC programme.

5.1 Carers UK

http://www.carersuk.org/help-and-advice

Summary:
Offers a range of general and specific information offering support to carers on issues including: financial, practical, health, work and careers, relationships, products, how to obtain support and resources. It also offers carers an opportunity to talk five days a week. Carers can download information on:

- **Attendance allowance**
- **Bedroom tax**
- **Benefit cap**
- **Bereavement**
- **Care act FAQ**
- **Care standards FAQ**
- **Carers allowance**
- **Carers assessment**

5.2 Sue Ryder

http://support.sueryder.org/

Summary:
Compassion in Dying: Your rights at the end of life (free to download) - Section 3 of the guide is about carers' rights, dealing mainly with a carer's right to information about the care of the person they are looking after; right to financial support; representing the person whom they are looking after and other support.

What to expect when someone important to you is dying. A guide for carers, families and friends of dying people (free to download) – This has previously been mentioned and appraised in *section 4.1*.

5.3 Dying Matters

http://www.dyingmatters.org/

Summary:
Remember when we…. (free to download) - Offers tips on how to start the conversation with someone who is dying, with respect to practical and emotional issues around their deaths.The leaflet offers principles to bear in mind, possible ways of starting the conversation, suggestions for during the conversation and sample phrases to use in this process. It can be accessed directly from:
www.dyingmatters.org/sites/default/files/user/images/Resources/Promo%20materials/Leaflet 6 Web.pdf

Find Me Help - Website offering links to local services and information which can be found by entering a postcode or location. For example, this includes local Macmillan Nurse teams on searching postcode M8 5RB plus Manchester Carers, Salford Carers and Anxiety UK

5.4 Get Palliative Care

http://getpalliativecare.org/

Summary:
While there are issues of translation into a UK context there are also some interesting items available from this US organisation. Many of the issues addressed relate to the personal concerns which underpin caregiving in any cultural environment. Relevant factors common to both the UK and US include how family experiences may evolve over time and how it can be beneficial to disassociate notions of palliative care from hospice care relevant only to the final days of life.

5.5 HealthTalk Online

http://www.healthtalk.org/

Summary:
This resource incorporates a great deal of information on many areas of illness and disease including material directly relating to carer support and needs. Carers can share the personal stories of other carers of someone with a terminal condition. Researchers talked to 40 people around the UK and carers can see and hear films of people describing various issues such as becoming a carer, impact on work and lifestyle and planning for death. Topics covered in the videos are grouped in the following categories:

Becoming a carer:
- **External help with caring**
- **Impact of caring at EoL**

Dying and Bereavement section:
- **Caring for someone with a terminal illness**

Living with Dying: the needs of carers:
- **Has a number of video clips and multiple links to other information.**

5.6 Macmillan cancer support:

https://www.macmillan.org.uk/

Summary:

At the end of life (downloadable factsheets) - Written for people who are dying of cancer and covers the last weeks, days and moments of life. Written for patients thus the tone and information is fairly generic and is of potential use to carers and people who do not have cancer. www.Macmillan.org.uk/Cancerinformation/Endoflife/Endoflife.aspx

5.7 Macmillan cancer support

https://www.mariecurie.org.uk/

Summary:

End of life: a guide (free to download) - Booklet designed for people who are dying and their carers. Covers the last few weeks of life, the last few days and nearing death. Includes emotional and psychological changes, physical changes and what happens as death approaches. www.mariecurie.org.uk/Documents/PATIENTS-CARERS-FAMILIES/publications-and-guides/end-of-life-guide.pdf

Changes in breathing patterns (free downloadable factsheet & short film) - Booklet designed for people who are dying and their carers. Covers the last few weeks of life, the last few days and nearing death. Includes emotional and psychological changes, physical changes and what happens as death approaches www.mariecurie.org.uk/en-GB/patients-carers/for-carers/practical-help/changes-in-breathing/

End of life (free from website) - Written specifically for carers. What to expect as a person is approaching death, including changes in body function, breathing and behaviour www.mariecurie.org.uk/en-GB/patients-carers/for-carers/end-of-life/

What to expect at death (free from website) - Written specifically for carers. Deals with what to expect as a person comes close to death, including physical changes, saying goodbye and preferences at time of death www.mariecurie.org.uk/en-GB/patients-carers/for-carers/at-death/

5.8 NHS Choices

http://www.nhs.uk/pages/home.aspx

Summary:

NHS choices have several resources which are helpful in both general commentary about end of life and the more specific aspects such as pain management - a major concern to most patients and carers. The site also provides filters which enable access to information which is disease/condition specific or where there may be overlap from multimorbidity e.g. dementia.

What end of life care involves - An overview of who offers end of life care and when such care begins; it also acts as a portal to information about other topics, such as ways for the dying person to begin talking to their families about their worries, concerns and wishes. www.nhs.uk/Planners/end-of-life-care/Pages/what-it-involves-and-when-it-starts.aspx

Lifting and handling - Provides helpful to carers offering advice on various lifting and handling issues and also flags up their rights as a carer in terms of free local authority training. It also advises about equipment and other issues. http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/mobility-problems-carers.aspx

A planner for EoL Care - Includes information for the patient and links to ACP considerations, carer support and organisations providing further information; this is largely aimed at patients but it does also have relevance for carers. http://www.nhs.uk/Planners/end-of-life-care/Pages/what-it-involves-and-when-it-starts.aspx

Managing pain and other symptoms - Offers information about medications that can help to control pain; it also deals with other symptoms such as nausea and vomiting, loss of appetite, and constipation which may be caused by the illness or be a side effect of medication. The site also includes comments from users of the site. www.nhs.uk/Planners/end-of-life-care/Pages/controlling-pain-and-other-symptoms.aspx

General EoL issues – Contains information on a) care and support, b) carers and end of life care, c) accessing palliative care, d) bereavement support, e) progression of terminal illness, f) registering a death, g) arranging a funeral, h) moving on as a carer. http://www.nhs.uk/CarersDirect/guide/bereavement/Pages/Overview.aspx

What to do after someone dies - Guide to legal obligations in the event of a death, plus issues such as the involvement of the coroner and arranging the funeral www.gov.uk/after-a-death/overview

5.9 Centre for palliative care (Australia)

http://www.centreforpallcare.org/

Summary:
Offers many cancer related resources.The following comprise appropriate sources for the MHMC team to consider:

Living with Cancer Education Programme (video) - A video covering topics on cancer, treatment, doctors, patients and carers, personal reactions and communicating with others.

A helping hand: a valuable resource for cancer patients, families and caregivers (DVD) – This provide a comprehensive interactive journey including unedited personal stories shared by cancer patients

Last Days of Living (video) - A video on the Montreal Palliative Care Service shows patients adjusting to the limitations of their progressive disease, the concept of family therapy and the importance of the multi-disciplinary team including music therapist, psychologist, physiotherapist as well as the nurse, doctor and social worker.

http://centreforpallcare.org/resources/

5.10 Forums and blogs

http://www.carersforum.co.uk/forum/index.php

http://www.carers.org/forums/

http://www.parents-and-carers.org.uk/cgi-bin/yabb2/YaBB.cgi

https://www.connectingforcare.co.uk/index.php/forums/

http://www.carersconnect.com/

http://www.carersuk.org/Forums

http://talk.nhs.uk/blogs/carers/default.aspx

Section 6. Good practice models

The initiatives in the first half of this section constitute a number of different ways of supporting people caring for those at the end of their life.

6.1 Carers Befriending Services - two examples

Central Lancashire Cancer Partnership Group - As part of the "Dying well at home: the case for integrated working" section on the SCIE website, the Carers' Befriending Service is a free service developed by hospice social workers and provided by trained volunteers who sit with a cared-for person in the carer's absence. The cared-for person must have a palliative diagnosis, be mainly housebound and socially isolated. The volunteer can sit with the cared-for person in their own home for up to four hours a week. The service aims to a) promote social, leisure and learning opportunities for carers, enhancing the health and wellbeing of carers, b) promote improved quality of life for the carer, thereby preventing breakdown, and c) provide reassurance to the carer in the knowledge that a trained volunteer is with the service user

Implementation of the service includes:

- **development of criteria, a referral form and risk assessment tool**
- **an 'interest' checklist to match potential befrienders with a cared-for person**
- **advertising for potential befriending volunteers (who complete application forms and are subject to Criminal Records Bureau checks)**
- **a three-day training programme for six potential befrienders**

Carers have taken breaks to attend medical appointments, relax or shop. Befrienders have provided psychological support to the cared-for person and their carer. The scheme links the cared-for person, their carer and the Family Support Team at the hospice. Befrienders have sat with the cared-for person in the final days of life and at death. Others have supported cared-for people when admitted as inpatients.

Contact:
Cheryl Scott,
Family Support Manager,
St Catherine's Hospital.
http://www.scie.org.uk/publications/guides/guide48/practiceexamples/practiceexample01.asp

Leicestershire County Council's Telephone Befriending Scheme - This scheme has been in place for two years. It originated as a pilot scheme funded through the council's carers grant allocation, but has now been 'mainstreamed' and is resourced using its main social care budget. It was developed to meet the needs of carers in the region who require help, advice and reassurance relating to any social care issue.

The scheme is run by volunteer telephonists (often carers themselves) who provide signposting to other services offered by the local authority; all volunteers are equipped with useful telephone numbers and contact details of Carers Project Workers and other key members of staff. The carers who use the service tend to be older people who have demanding caring roles. All calls are logged by the volunteers. The scheme has been approved as a mentoring scheme via the nationally recognised quality assurance body.

The manager of this scheme reported that it had proved very popular with carers who used it (their numbers were not known). The scheme is promoted and publicised through a range of local activities (such as those linked to ‘Carers Rights Day’) and through voluntary organisations and public venue using leaflets, posters, etc. Recently Leicestershire County Council has been considering expanding the scheme to reach out and engage BAME carers, although it is thought additional funding will be needed for this, because difficulties are envisaged in identifying volunteers who speak different languages. The project manager believed it would be useful to explore others ways of using what is termed Information Communication Technology (ICT) to reach carers. Although newsletters are already offered by email, many carers registered with the council are older people providing high levels of care and that few carers in this group chose to receive the newsletter in an electronic format. A recent evaluation of care-related services, conducted with 300 carers and using a questionnaire available in both paper and electronic versions, elicited 120 responses, only 6 of which sent electronically. Similar ICT initiatives could constitute a reduction in service costs and an increase in the effectiveness of services (Yeandle, S. and A. Wigfield 2011).

6.2 Compassionate community networks: supporting home dying

This community project being developed at Weston-super-Mare, UK, explores how communities can be mobilised to help someone dying at home. A health professional mentors the dying person and their carer to identify and match: (a) the tasks that need to be done and (b) the members of their social network who might help with these tasks. Network members may subsequently join a local volunteer force to assist others who are network poor. Performing practical tasks may be more acceptable to some family, friends and neighbours than having to engage in a conversation about dying, and provides a familiarity with dying that is often lacking in modern societies, so in this model, behavioural change precedes attitudinal change. The scheme rejects a service delivery model of care in favour of a community development model, but differs from community development schemes in which the mentor is a volunteer rather than a health professional, and also from those approaches that strive to build community capacity before any one individual dying person is helped. There is a need for evaluation of this and similar schemes, and for basic research into naturally occurring resource mobilisation at the end of life (Abel, Bowra et al. 2011).

6.3 Developing training for supporters of lay-carers involved with home based end of life care: a participatory approach

Much current policy aims to enable more people to die in the place of their choice, and increase the number of people who die at home. Essential to this aspiration is the involvement of lay-carers, usually family or friends of the ill person. The importance of this role is acknowledged at a national level, however carers continue to report many unmet emotional and practical support needs. Innovative approaches are required if we are to improve the experiences of lay-carers in end of life situations. This post presentation reports on the progress of an innovative participatory research project, which is developing training for people who support carers. It is intended to provoke discussion with other health providers.

The project aims to develop and pilot an introductory training programme for supporters of carers in end of life situations, such as support workers and volunteer mentors. Participatory action research methods have been used to engage with stakeholders including carers and carer support organisations. The programme is being piloted from January 2014.

Current evaluative activities indicate that this developing programme will be acceptable to a wide range of stakeholders. Ongoing piloting and evaluation will further test the utility of the programme.

Participatory research methods are a useful way to engage with a range of stakeholders and to raise awareness of end of life care issues. At the end of this project, the training programme will be publically available and free to use (Hardy, Caswell et al. 2014).

6.4 The needs of older carers

This joint initiative between Age UK and the DoH, began in 2010 and focuses on the needs of older carers. The idea being to empower older carers by focusing on their practical and emotional needs and helping them to be more effective in their support to their relative or friend.

The three-year project began with Age UK Leeds and Age UK South Tyneside, joined in 2011 by Age Concern Kingston upon Thames and Age UK Leicester, Shire and Rutland. In 2012, the newly developed procedures and protocols were extended to Age UK Oxfordshire and Age UK Lancashire.

All the local bodies involved have to identify a project manager to run their pilot and recruit volunteers who can offer relevant services to carers and their relatives and friends. Volunteers can either provide support themselves or signpost the carers to Age UK or external practical services such as shopping, cleaning, gardening, food delivery and benefits advice.

There are examples of partnership with social services (for complex cases), local hospices and voluntary sector organisations.

Volunteers can also arrange or provide emotional support to older carers, such as advocacy services, counselling, befriending or spiritual assistance, to enable them to care for people at the end of their lives, in their own homes. Anecdotal evidence suggests that the service has benefited both carers and the relatives being cared for.

Contact:
Linsey Reynolds,
Programme Manager,
Age UK.
http://www.scie.org.uk/publications/guides/guide48/practiceexamples/practiceexample11.asp

6.5 Extra help at the EoL

Age UK Northamptonshire provides care to people in the last weeks of their life, which enables them to remain at home with their loved ones. This service is currently only available by referral from GP or hospital staff.

Telephone: 0845 677 2220
Email: northamptonshire@ageuknorthants.org.uk

6.6 Hospice at Home

There are a number of hospice at home services throughout the UK which extend hospice care into the community to support patients with palliative care needs. Such care is based on the Hospice philosophy which values each patient as an individual and recognises the need for family/carer support. The service described here operates as a partnership between Rossendale Hospice, social services and the local primary care provider. Care packages include social care, a combination of both social and nursing care, leading to enhanced specialist palliative nursing care, working closely with district nurse, macmillan nurses, GPs and social workers. It is led by a senior nurse team leader and a staff nurse who manages a team of health care assistants and ad-hoc registered general nurses. HCPs are specially trained in caring for patients and their families/carers with a terminal illness.

The aims of hospice at home, in general, are:

- **To give more choice and support to those who wish to live, be cared for, and to die at home**
- **To give the highest possible standards of nursing care, offering advice on pain and symptom control, as well as emotional and practical support for the patient and their carers**
- **To work closely with the patients, district nurses and GPs to ensure seamless and holistic palliative care may be given to the patient and their carers**

Care is delivered seven days a week including Bank Holidays. Night care is also available subject to individual patient need.

The referral criteria comprises:

- **The patient must agree to the referral**
- **The patient must be an adult over the age of 18 and reside in Rossendale**
- **The patient must have palliative care needs, with a life limiting illness**

For a Hospice At Home PDF guide contact; the hospice at home team in Rossendale, on 01706 253633
http://www.rossendalehospice.org/patient-carer-services/hospice-at-home.html

6.7 The green card scheme

Lincolnshire Community Health Services. The ‘green card’ scheme provides a system where patients with palliative care needs can have fast track access to out-of-hours (OOH) services and have direct contact with an experienced clinician. The scheme was a joint initiative between OOH and Macmillan in 2006. The green card system has significantly reduced the need for patients and their carers to phone 999 thus avoiding inappropriate hospital admissions.

https://www.cqc.org.uk/sites/default/files/ry5_coreservice_end_of_life_care_lincolnshire_community_health_services_nhs_trust_scheduled_20140905.pdf

6.8 Massage techniques

Butterwick Hospice in County Durham has an aromatherapy service that includes education in massage techniques for carers.

www.sevenwellbeingcentre.org.uk

6.9 Complementary therapies for carers

St Christopher's Hospice in London gives free access to complementary therapies (aromatherapy, hypnotherapy, reflexology and relaxation) provided in the community by dually trained specialist palliative care nurses.

http://www.stchristophers.org.uk/leaflets/complementary-therapies

6.10 Moving and Handling

6.1 NHS Moving and handling the person you care for

This site is helpful to carers offering advice on various lifting and handling issues and also flags up their rights as a carer in terms of free local authority training. It also advised about equipment and other issues.

http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/mobility-problems-carers.aspx

6.2 NHS Forth Valley

Moving Forth - Moving up the bed for a person who requires assistance from two carers (Video). This site has several videos on the subject of moving and handling including catheter care.

https://www.youtube.com/watch?v=dHxzxXoEeyM

6.11 Health and safety courses - St John's Ambulance

Runs moving courses for professionals and first aid for the general public

	Duration
Fire marshal (fire warden)	1/2 day
Fire marshal refresher	2 hours
Health and safety basics	2 days
IOSH working safely	1 day
IOSH managing safely	4 days
Risk assessment	1 day
Display screen equipment risk assessment	1 day
Moving and handling principles	1/2 day
Moving and handling people	1/2 day
Moving and handling for first aiders	1 day
Stress management	3 hours

First aid courses	Duration
Essential first aid	2 hours
Essential first aid (all ages)	3 hours
Basic first aid	3/6 hours
Activity first aid	2 days
Basic sports first aid	1 day
Essential and basic first aid	6 hours

http://www.sja.org.uk/sja/training-courses/courses-for-the-general-public.aspx

6.12 Partnership for excellence in palliative support (PEPS) pilot - Sue Ryder & Bedfordshire

★★

The PEPS service was a finalist for the 2012 HSJ award in the Patient Centred Care category. It was included as a best practice case study example by the National End of Life Care programme. Results of the pilot have been positive, attracting national coverage, with Clinical Commissioning Groups across the UK showing an interest in this initiative.

PEPS aims to improve the care experience for patients in the last 12 months of life and to help health and social care professionals provide care in the place where patients choose to be at the end of their lives. That is, predominantly at home. PEPS is a service that provides 24-hour support to patients in the last year of life and coordinates palliative care across Bedfordshire.

PEPS provides a single, 24 hour telephone number point of contact providing a seamless service for patients, their carers and care professionals when advice and support are needed, 15 organisations are formally bound together in a 'hub and spoke' model, and with a shared memorandum of understanding. The service sees qualified nurses and senior nurses, experienced and skilled in palliative care, as the first point of contact to screen calls to quickly identify the most appropriate health or care professionals to respond to the caller's needs.

The coordination centre - hosted by Sue Ryder at St John's Hospice in the village of Moggerhanger in Bedford, uses a shared electronic record on SystemOne to ensure patients' records are readily available. These give nurses up-to-date information about the patient's condition (with consent) and the patient's preferences and choices. These records also fulfil the requirement to have an electronic (EPaCCS) register of palliative patients.

Alongside the introduction of the coordination centre, out-of-hours services, including face-to-face nurse assessment and a palliative care support worker service, have been established countywide to enable patients to be cared for at home.

6.12.1 PEPS aims

- **Empower patients to be cared for in their preferred place**
- **Provide high-quality care delivered by the right provider, in the right place, at the right time**
- **Provide support and advice to the patients' families and carers**
- **Deliver improved outcomes and experience**
- **Deliver the national quality target, SQU02, to increase deaths in usual home**
- **Deliver the regional target to increase the number of patients held on the central end-of-life care register**
- **Reduce expenditure on unplanned admissions, length of acute hospital stay and accident and emergency attendances**

The service is part of the quality, innovation, productivity and prevention programme for NHS Bedfordshire and plans to provide data to support palliative care service planning by future Clinical Commissioning Groups. The initiative was proposed by the Palliative and End of Life Care Local Implementation Group, whose members are key partners and stakeholder organisations, including carer representatives who were instrumental in shaping the service.

6.12.2 PEPS evaluation

PEPS has been evaluated over one year. The evaluation examined:

- **Activity during the pilot**
- **Impact on emergency hospital admissions for palliative and end of life patients**
- **Impact on length of stay for patients who are admitted to hospital as an emergency**

- **The cost benefits associated with the reduction in emergency admissions and length of stay**
- **The views of stakeholders**

It was shown to have positive impacts. In the first five months of operation:

- **PEPS has co-ordinated the care of 415 patients, 68 per cent of whom died at home, as they wanted**
- **Only 10 per cent died in hospital matching national preferences and contrasted with 2012 England statistices of 42% of home deaths and 52% in hospital**
- **Following PEPS referral there were 30% fewer emergency hospital admissions with a 30% shorter length of stay and a reduction in cost of around £300 per admission**
- **PEPS was highly valued by stakeholder, especially GPs**
- **Most referrals (68%) were made by Macmillan Nurses and increasingly as the service is becoming known, by district nurses**
- **35 % of calls to the service were made by patients' relatives**

6.12.3 Findings to date

- **Hospital engagement has led to improved integration of acute and community care**
- **The MDT team, through working with PEPS, are discharging patients home more rapidly**
- **The co-ordination centre has been instrumental in supporting families between discharge and start of care package arrangements. Patients and families report feeling "secure" and "not feeling left alone"**
- **Feedback about the service has been "fantastic" from patients, their relatives and GPs**

Capturing preferred and actual place of care and death is a service outcome that will be continually measured. The School of Health and Related Research at Sheffield University will assess the economic impact of the service.

http://www.hsj.co.uk/resource-centre/best-practice/commissioning-resources/how-to-put-patients-at-the-centre-ofpalliative-care/5046125.article#.VSVjhzHF8pU

Contact:

Jo Marshall,
Business Development Manager,
Sue Ryder PEPS (Partnership for Excellence in Palliative Support)
http://www.sueryder.org/~/media/Files/What-we-do/Care-centres/St%20Johns%20Hospice/PEPS%20pilot%20evaluation.ashx

6.13 WIRED – Oldham

http://www.oldham.gov.uk/info/200244/caring_for_someone/508/wired_oldham_carers_centre

Oldham Carers Centre offers a range of free services for unpaid Carers across Oldham. For anyone caring for a partner, family member or friend. Oldham Carers Centre assists with information about:

- **Health issues**
- **Entitlements**
- **Mobility**
- **Equipment**
- **Volunteering opportunities**
- **Carers Individual Budgets**
- **Carers rights**
- **Carers employment issues**

The centre also provides the following services to carers:

- **One-to-One Practical and Emotional Support (over the phone, call in, home visits)**
- **Carers Assessments**
- **Carers Individual Budgets**
- **Signposting / Referrals to Social Services and Other Providers**
- **Advocacy Service**
- **Counselling Service**
- **Oldham Carers Emergency Support Scheme (OCESS)**
- **Information, Advice and Guidance**
- **Volunteering Service**
- **Stress Reduction Courses**
- **Weekly Carers Social Club (Drop-in Sessions)**
- **Activities/Talks/Training/ rips**
- **Reiki, Massages, Facials and Reflexology**

6.14 BAME.

6.14.1 Ansaar (Leicester)

Ansaar provides a support network for Asian Family Carers in Leicester through the Asian Family Carers Support Service. This includes:

- **Information about Carers Rights**
- **Regular meetings and events**
- **Support to access services for health, social care, leisure and education**
- **Access to information and advice on welfare benefits, housing, employment, consumer debt, social care etc.**
- **Support to access training and employment opportunities**
- **1:1 counselling is available in English, Albanian, Polish, Urdu, Arabic, Bengali, Hindi, Farsi, Punjabi.**

6.14.2 African Afro-Caribbean Support Network (AACSN). Waltham Forest

The AACSN is based in the London Borough of Waltham Forest but has an increasing presence in adjoining boroughs such as Redbridge, Newham and Haringey. Established in 1999 and a registered charity since 2004 they work to raise awareness of the specific needs of black and minority ethnic carers and people with severe learning disabilities, mental health needs and other health conditions. They offer support, information, guidance on accessing services, advocacy and health promotion.

http://find.redbridge.gov.uk/kb5/redbridge/fsd/home.page
112 Melbourne Road,
Leicester.
LE2 0DS

6.14.3 Apna Group Project

Offers day time opportunities for BAME adults with a separate women's group which caters for cultural and linguistic needs. Apna provides social, leisure, educational and health-related activities three days a week. The aim is to maximise the potential and independence of users. It promotes opportunities to integrate in the wider community by accessing all services. Users sustain Apna by using their personal budgets to access its support.

http://www.familycarers.org.uk/resources/by-tag/black-minority-ethnic-carers

It would be useful for the MHMC team to look at the following web resource as this provides information further information about BAME initiatives across the UK http://www.familycarers.org.uk/resources/by-tag/black-minority-ethnic-carers

6.15 Carer support pathway in EoL care - Yorkshire and Humber

Although this EBS did not intend to cover care support pathways, this piece of work appears pertinent to include in the report and may be of interest to the MHMC team. It is based on a six month pilot project funded by Yorkshire & Humber improvement partnership and the Department of Health Carer's Resource, to identify needs and recommend solutions for supporting carers during the 'final year of life' phase of a caring role.

This project aimed to identify existing provision in carer support services, identify gaps and create a pathway showing when, how and where carer support is and/or should be offered. The project was delivered in partnership with various teams based in hospitals, clinics and community settings. 95 carers participated and established the essential needs of carers for support during the EoL stages including appropriate locations, timing and format. The project looked at specific aspects of support including financial, emotional and practical needs of carers and assessed the best routes for accessing additional support outside the project itself, if required.

The project team identified great partnership opportunities linking with health and social care teams and built strong relationships with existing palliative care services. With feedback from carers and staff, the project team was also able to identify areas for improvement in future delivery including referral mechanisms and triggers, major gaps in service provision around distance support, communities of interest and carers in employment.

The recommendations from the project have helped draw up a carer support pathway which harmonises with the existing DoH EoL care (patient) pathway and offers guidance and suggestions based on our evidence and findings to recommend how the proposed stages could be implemented.

Among the recommendations are:

- Provision of specialist help for carers/caring families in their own right

- Links to primary care and use of the EOL register for identification and referrals
- Co-location of teams to facilitate referral and feedback plus information sharing
- Joint working between carer specialists and community liaison posts
- Options around assessments to reduce duplication and increase value
- Practical bereavement help and better chance for feedback

Areas to develop/gaps identified:

- Earlier identification and referral of carers is needed – the last few days/hours of the patient's life is too late to introduce carer support and the workers are unable to make a real difference. Carers should be identified early and referred for support before crises are reached and time is running out.
- Carers and professionals need to understand the service is available to them from the moment of diagnosis so they can build a relationship and access it as suits their needs. Work here needs to identify possible trigger points for different stages of health care, to enable identification as early as possible, including linking with GP palliative care registers etc.
- Emotional support is vital - personalised support for the carer is the most highly sought after and valued aspect of this work.
- There is a real need for the opportunity to talk openly, without guilt, with less time restrictions than in clinical settings to a specialist 'listener' who will travel the pathway with the carer.
- Distance support – one of the areas we identified as a need for further, specialist support was where a caring relationship was taking place 'at a distance', this included members of the armed services, students away at university or prisoners. In these cases the carers are still struggling to come to terms with the situation and in need of help and support but this can be very difficult in terms of communication and access to help. The help they require is different – less practical and more emotional and information sharing to feel they are still a part of the family.[21]
- Impact of employment – many of the carers were working full or part-time. They were having real difficulty both accessing information/ support from clinical staff out of hours and also experiencing lack of understanding of the situation and support from employers. The
- need for an advocate (who can operate alongside the carer in these situations) asking questions, relaying information or explaining difficulties to other professionals and employers can be crucial in helping carers maintain their employment or better understand and support their loved one.There may also be a role for working with employers to better understand the situation and how to provide better working practices, policies and carer awareness.

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[21] *This needs further consideration and exploration for potential joint working with services that do exist or the development of new ones.*

- No statutory input - there was difficulty for carers accessing support (including bereavement support) in cases where the patient was refusing to accept help/input from any statutory services. This meant carers were often not identified, nor referred for support in their own right to statutory services. This also happened if the level of need was deemed ‘too low’ for statutory eligibility criteria.

More information is available from:
https://www.adass.org.uk/AdassMedia/stories/Policy%20Networks/Carers/TCRCarerSupportPathwayEndOfLifeFull.pdf

6.16 Web-based initiatives

It has been suggested that future work on interventions to train and support carers should focus on web-based initiatives (Hudson and Aranda 2013). Three initiatives are described below:

6.16.1 The Multimedia example; a multimedia resource to support family carers of people receiving palliative care.

http://centreforpallcare.org/research/completed-projects/a-multimedia-resource-to-support-family-carers-of-people-receiving-palliati/

***Project team**:* Dr Kristina Thomas & Gaye Moore

Partners: Melbourne City mission Palliative Care

Duration: 12-months commenced in May 2010.

Purpose: This project will develop and evaluate a multimedia resource for family carers of people receiving palliative care to provide them with information and support related to the role of caring for someone with advanced disease. This study will be directed by a steering committee of past and current carers who will determine the type of information to include in the resource and will assist in developing the evaluation of the resource.

Method: The evaluation of the resource will include focus groups with carers and health professionals. Consumer involvement in the project will also be evaluated by conducting semi-structured interviews with the steering committee members.

Results: Not reported yet

6.16.2 Carers in Hertfordshire web pages (1)

It offers the following benefits:

- An opportunity to join an information mailing service and receive a copy of the local authority's countywide publication "Carewares" and newsletters four times a year
- Help in planning the practical support that carers need in their caring role
- An opportunity to request a planning support phone call
- An opportunity for carers to get involved in discussions, listening events and consultations or to become a carer trainer
- An opportunity for carers to acquire details of how to express their views and have a voice with other carers in the county
- Carers can attend workshops and activities with other carers

The 'How can we help?' page on this website covers: Informing carers of their rights.

- How the local authority will spend time helping carers plan the support they need by problem solving and telling them about local services and specialist organisations that may support them
- Telling carers about ways they can look after their own health, meet other carers and add their voice to influence provision of services
- Contact details if carers are new to caring or have been a carer for many years, if they live with the person they care for or they live elsewhere (Yeandle and Fry 2010)

6.16.3 Carers in Hertfordshire web pages (2)

The 'Planning the Support Carers Need' offers free and confidential services:

- Support to continue in the caring role or support to make the choice to change or stop your caring
- Ways to help carers have time away from your caring responsibilities to rest, pursue interests, spend time with friends or have a holiday
- Concerns about the cost of caring, benefit checks, potential financial support,funding for holidays, equipment or extra support
- Caring may affect your own health. We can help you to lessen your anxiety, stress and isolation with information, for example, about relaxation or lifting skills and encouragement to take part in activities

- Ensuring carers know their rights as an employee, assess the impact of any work-related decisions and what services are available for the patient (Yeandle and Fry 2010)

Section 7. Social action projects

The Social action projects in the second half of this section are part of “End of Life Care: Community and society and National Health Service.” The Cabinet Office has awarded more than £800,000 to 7 social action projects across the UK, providing compassionate support to people at the end of their lives and to their families. All of these valuable projects **harness the power of volunteers** to provide befriending and practical support for people approaching the end of life and their families. Through the projects volunteers will help to tackle loneliness and isolation, which people at the end of their life can often experience. Volunteers will provide companionship and emotional support, as well as practical support to help people reconnect with their own communities. The International Observatory on EoL care undertakes high quality research, clinical studies, evaluation, education, advocacy and consultancy to improve palliative and end of life care for patients and family carers. The Observatory works closely with the local health and social care community in the North West, as well as nationally and internationally. The following projects relevant to this scan are being assessed by the Observatory.

http://centreforpallcare.org/index.php/research/ipcfcrc/

7.1 Volunteer-led befriending service

St .Michael’s Hospice and Odiham Cottage Hospital in Harrogate delivered by St Michael’s Hospice, North Hampshire. Volunteers will befriend people identified as isolated, including people living in rural seclusion. As well as traditional face-to-face befriending, the service will make use of digital and online networks.

By commissioning an early intervention service that provides social interaction and companionship, Odiham Cottage Hospital has agreed to fund a volunteer-led befriending service, operating three days a week. Working in partnership with St. Michael’s Hospice, with referrals via The Maple Integrated Care Team, the service aims to enhance the quality of life for adults suffering with a life-limiting illness and/or palliative care needs.

This is done by offering clients the opportunity to reduce social isolation and to form a trusting relationship with volunteer befrienders, which in turn may enable people to:

- acquire a greater degree of self-confidence and emotional growth
- enhance their capacity to make use of their own resources, as well those resources available to them within their community, i.e. other voluntary organisations/statutory agencies
- cultivate and maintain relationships with others while re-connecting with their local community

Volunteers will also be able to provide advice and signpost people to other guidance they might need. A number of the shortlisted projects will work with groups who have difficulty accessing support. The impact of the successful social action projects will be evaluated by the International Observatory on EoL care at Lancaster University and the Institute for Volunteering Research. The evaluation will make an important contribution to the evidence base for the impact of social action in this area.

7.2 Sue Ryder National Befriending Service

Befriending and Buddying can involve volunteers supporting service-users by:

- providing companionship and conversation
- enabling individuals to maintain hobbies and interests
- running occasional errands for a patient
- helping access local community activities and resources
- sign-posting to other services where appropriate

Befriending and buddying involves getting to know an individual service-user, providing a regular, reliable source of support through face to face visits, telephone calls, or a combination of both. It requires a commitment from volunteers and the following attributes:

- a good communicator
- patient and understanding (e.g. to allow sufficient time for residents with speech difficulties to express themselves)
- friendly and approachable, with a sensitive and caring manner
- reliable and emotionally resilient
- able to use their own initiative

7.3 BAME. Compassionate Communities

St Joseph's Hospice will work with Turkish/Kurdish and Afro Caribbean communities in Hackney, BAME communities in Newham, and the Bengali community in Tower Hamlets, East London to develop social networks.

7.4 Gentle Dusk - Future Matters

A community outreach programme in North London, established by Gentle Dusk.

Trains volunteers from third sector and community organisations to become peer educators in EoL care planning. They are then able to cascade information to members of their local communities and enable and support communities to put their end of life care plans in place.

Future Matters http://www.gentledusk.org.uk/future-matters.html

7.5 Volunteer visitor service

St Michael’s Hospice in Hampshire. Volunteers will provide weekly companionship to people living at home as well as respite to their carers, including those isolated by geography in the largely rural catchment area. The Volunteer Visitor service provides reliable practical and social support to patients in their own homes. Volunteers can help with a range of tasks, shopping, light household tasks, accompanying people to appointments, and simply being there and listening.

This support allows carers to take a valuable break, helping to reduce the strain and helping them to feel confident that they can continue their caring role for as long as possible. The service is the only one of its kind in the Harrogate district and is open to anyone over 18 years of age who is living with a terminal illness.

All volunteer visitors are fully trained and are supported by a range of Saint Michael's community specialists, including occupational therapisst, social workers, physiotherapists, specialist MND practitioners, and the community clinical nurse specialist team. All volunteers are supervised by members of the patient care team and are thoroughly checked by the Disclosure and Barring Service (DBS). The volunteer visitor role does not include any personal care, clinical care or domestic duties and is not designed to replace any professional carer function.

7.6 The Herts neighbours project

Delivered by Peace Hospice in partnership with St Francis Hospice, Hertfordshire Community NHS Trust and Hertfordshire County Council. Volunteers will provide companionship and practical support, including helping people to use social media to reconnect with loved ones. The Herts Neighbours Project is the Watford and West Herts section of a wider study which aims to assess the effect of services provided by volunteers in the community.

7.7 Martlets home visitors network

Martlets home visitors delivered by Martlets Hospice, Hove. The service will provide social contact and practical support to people living at home, with a focus on helping people through the process of leaving a hospice to return home, which can be a time of worry and distress for many patients.

https://www.gov.uk/government/news/800000-for-social-action-projects-that-support-people-at-end-of-life

http://www.southglos.gov.uk/Documents/beyond_we_care_too.pdf

Section 8. End of life carer support, strategies, guidelines

The National Council for Palliative Care (NCPC) is the umbrella charity for all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland. They believe that everyone approaching the end of life has the right to the highest quality care and support, wherever they live, and whatever their condition. They work with government, health and social care staff and people with personal experience to improve end of life care for all. NCPC leads the Dying Matters coalition which aims to change public attitudes and behaviours around dying, death and bereavement.

www.ncpc.org.uk

http://centreforpallcare.org/resources/

The following constitute models of good care and strategies from government and palliative care organisations to facilitate carers undertake their role, and most encompass the beliefs of the NCPC.

8.1 Recognised, valued and supported: what happens next for the carers strategy

This reports sets out how the government will work with carers and carers' organisations. Local and national government are expected to reciprocate the support carers show with measures that ease their caring responsibilities. In November 2010, the DoH awarded almost £2 million in grants to Carers UK, Crossroads Care, The Princess Royal Trust for Carers, Partners in Policymaking, The Afiya Trust and The Children's Society to support their work with carers. In addition, it has launched the reaching out to carers innovation fund to encourage patient-led and condition-specific voluntary organisations to focus more on how they can support carers, as often they are the first port of call for information when someone takes on caring responsibilities. An additional £400 million was provided via the NHS over four years to provide carers, including young carers, with breaks from their caring responsibilities.

This strategy sets out the government's commitment to ensuring that carers are able to take breaks from caring in order to sustain their role as a carer and, where possible, to enable them to continue working where that is their desire. The vision of this strategy is that carers will be universally recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to meet individuals' needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring, while enabling the person they support to be a full and equal citizen.

The outcomes envisaged encompass the following:

- Carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role
- Carers will be able to have a life of their own alongside their caring role
- Carers will be supported so that they are not forced into financial hardship by their caring role
- Carers will be supported to stay mentally and physically well and treated with dignity
- Children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive and to enjoy positive childhoods

The report identified the following priority action areas:

- Supporting those with caring responsibilities to identify themselves as carers at an early stage
- Recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages
- Enabling those with caring responsibilities to fulfil their educational and employment potential
- Personalised support both for carers and those they support, enabling them to have a family and community life
- Supporting carers to remain mentally and physically well (DoH 2010).

8.2 The EoL care strategy 2012 - UK government report

The strategy predominantly relates to the collection and interpretation of data about experiences of caring and the structure of training/education for formal (paid) carers in care homes and similar settings rather than the information/skill needs of informal (family) carers. This strategy was initially launched in 2008 and states that, wherever possible, people should be able to spend their last days in the place of their choosing. It is primarily focused on patient needs and outcomes but has sections on the utility of advanced care pathways addition to patient-centred information, some of which is now obsolete e.g. Liverpool Care Pathway. Most people say that they would prefer to receive this support in their own home. For people who move to live in a care home, that becomes their home. Since the launch of the strategy in 2008, the fourth annual report confirms that almost 30,000 more people have been able to die where they usually live - at home, or in a care home.

Main points in this strategy are that:

- Nationally, 42.4% of people are now dying at home or in a care home
- “Dying Matters” continues to make major strides towards engaging the public and tackling the taboo of discussing death and dying, its membership now standing at more than 20,000 people

- GPs are being encouraged to engage with patients who might be in their last year of life, so that they can undertake end of life care planning with them
- Findings from the first ever national “VOICES” survey of bereaved relatives provided a mine of fascinating information on the quality of care delivered in the last three months of life. Hospice care was the most highly rated, followed by care at home. A second “VOICES” survey will more depth and understanding to how people experience EoL care
- The National End of Life Care Intelligence Network has added significantly to the information available and useful to both commissioners and providers in order to carry out their roles
- Public Health England will continue to host the End of Life Care Quality Assessment (ELCQuA) tool for benchmarking and tracking progress, revised to align it to the new NICE Quality Standard for end of life care for adults
- In April responsibility for the End of Life Care Strategy will move from the Department of Health to the NHS Commissioning Board where it will be the responsibility of the Board’s Medical Directorate. The work will form part of a domain 2 which is concerned with long-term conditions
- Clinical Commissioning Groups (CCGs) are beginning to pick up their role in commissioning and promoting End of Life Services
- To support its end of life pathway, the NEoLCP (National end of life care programme [22]) has been working with a network of about a hundred CCGs to ensure not only that they know about the wealth of resource already available to them on end of life care, but that support can be tailored to needs. The NEoLCP has also been supporting a network of about 360 EoL care facilitators, who are based in all parts of the service, and has established a new group of more than a hundred social care champions

These people will help to ensure that end of life care is embedded in new plans in the future health and social care landscape. Over the next year the focus will continue to be on supporting people to be cared for and to die in their place of choice, providing community-based services to enable this to happen with integration of services being key. Palliative Care Funding is progressing as eight pilots begin to generate the data needed to take forward the work started by the independent Palliative Care Funding Review.

https://www.gov.uk/government/publications/end-of-life-care-strategy-fourth-annual-report

www.goldstandardsframework.nhs.uk

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[22] *http://healthcare.trinityhospice.co.uk/wp-content/uploads/2014/11/A5a-i-NEoLCP-End-of-Life-Care-Pathway-resources.pdf*

8.3 Task force on family carers: recommendations from the European Association for Palliative Care (EAPC)

The EAPC task force on family carers was established in October 2008 with the purpose of promoting the development of support for family carers and to increase the recognition of their role in providing care to patients with advanced disease. To achieve these aims, the Task Force have prepared an official position paper which provides an outline of the roles and needs of carers and recommendations to support them. This was approved in March 2010, by the EAPC Board who work in close collaboration with the International Palliative Care Family Carers Research Collaboration (IPCFRC). In relation to this EBS, Part 2 of this White Paper considers existing interventions and services developed to address carers' needs, makes recommendations for improving support and services to carers and outline areas where further research is needed.

Evaluations of interventions for carers rarely assess specific outcomes, added to which is the well documented challenges of undertaking palliative care research. However, they do show that carers have ubiquitous needs, including:

- Psychological and emotional support
- Information
- Help with personal, nursing and medical care of the patient
- Out-of-hours and night support
- Respite
- Financial help (EAPC 2010)

8.4 A review for the commission into the future of hospice care in the UK

This review is relevant because, although it relates to hospice care, as identified in the scan, there is a connection between home and hospice care and how best to work with, and for, family carers of those facing end of life. The report confirms that many of the gaps and needs identified in earlier research or policy initiatives still exist and further observes that increasingly complex health and social care responses to terminal illness produce a correspondingly greater need for family carers to navigate multiple sources of support and types of information.

Relevant to the programme envisaged by the Trust, the report notes the need for family carers:

- to be teated respectfully and compassionately
- to be recognised as experts in relation to the cared-for person and

- to have access to information and up-to-date knowledge about how to provide care

Key messages emerging from this review are worth noting:

- Carers can both be giving and receiving care – they may be trying to meet competing demands to attend to their own health while at the same time supporting the cared-for person
- Carers may experience considerable physical, psychological, social and financial challenges which they are largely unprepared for
- There is evidence that carers perceive that they have little choice in decision making about their role and the nature of care provision
- Little is known about the full economic cost for individuals in providing EoL care and about how the control of personal, social and health care budgets will affect carers of those near the end of life
- Changes to employment patterns with more female workers, delayed pension entitlement, and more part-time working, are likely to mean that more people will be required to combine paid employment with care provision

Of particular importance to the content of the proposed trust programme are those elements of carer support need defined as ‘information, training or education’. These constitute:

- Strategies for safe moving and handling of the patient
- Information resources on disease process, trajectory and prognosis
- Information on how to provide specific care tasks, equipment and medication
- Information about the dying process and symptom management in a timely way
- Access to welfare or benefits advice

There has been a history of policy changes designed to benefit carers, but the experiences of family carers of those approaching the end of life appear to be largely unchanged and continue to be unnecessarily challenging. While support for carers is a key aspect of hospice care, the Commission called for a shift in its culture to truly include family carers as central in their relationship with patients and as worthy beneficiaries of support both during and after the death of the patient. The Commission report on supporting family carers is available to download, along with some resources to help hospice care providers improve their support for carers. The main way in which to achieve this is by the following methods:

- Developing the role of the clinical nurse specialist in palliative care in the future
- Creating mature partnerships with community nurses that support the inevitable blurring of roles and task allocation
- Delivering highly skilled palliative care for all who could benefit from it regardless of diagnosis
- Providing care such as venipuncture, in addition to advice and support

- Delivering advanced nursing skills such as prescribing and clinical assessment
- Developing new skills in patients, families and family carers including health literacy
- Developing more sophisticated partnerships with patients and families as a basis for sharing risks around treatments
- Providing expert care

http://www.helpthehospices.org.uk/our-services/commission/resources/

8.5 Guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients

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To download a copy of this booklet or a copy of the complete version of the guidelines, which includes the methodology and the literature review that supports the guidelines, please go to www.centreforpallcare.org

8.5.1 Description and rationale

Support for family caregivers, including bereavement follow-up, is a core function of palliative care.

Methods: (1) Literature review; (2) focus groups and structured interviews with key stakeholders within Australia; (3) national and international expert opinion to further develop and refine the guidelines using a modified Delphi process; and (4) endorsement of the guidelines from key palliative care, caregiver, and bereavement organizations (national and international).

Purpose: To develop clinical practice guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients.

Results: The guidelines were developed for multidisciplinary health care professionals and clinical services commonly involved in caring for adult patients receiving palliative care in a variety of care sites throughout Australia. These consensus-based guidelines have been endorsed key Australian and international organisations.

Conclusions: The guidelines may prove valuable for the international palliative care community and for generalist health care providers who occasionally care for palliative care patients. Research is recommended to explore the uptake, implementation, and effectiveness of the guidelines.

The evidence to support the guidelines was rated in accordance with the National Health and Medical Research Council (NHMRC) (Australia).

8.5.2 Details of the guidelines

Part 1: Setting Up Family Caregiver Support

Guideline 1. Once a patient has agreed to receive palliative care, inform the patient that the role of palliative care is also to support family caregiver(s). The family caregiver(s) will be a person(s) who the patient perceives to be his or her most important support person(s). This may be a family member, partner, or friend and may not necessarily be his or her next of kin.

Guideline 2. Ask the patient to identify the primary family caregiver. Where only one family caregiver is identified, ask the patient if there is another family member or friend who may be willing to be approached and act as an additional family caregiver. Discuss the patient's preferences for the involvement of the family caregiver in medical and care planning discussions and note this in the medical record and care plan.

Guideline 3. Confirm with the family caregiver(s) that they understand the patient has nominated them for this role. Explain the typical role and responsibilities of the family caregiver and confirm they are willing to accept this responsibility and note this in the medical record. Discuss any concerns that the family caregiver may have in accepting this role (including possible conflicts with other family members).

Guideline 4. Discuss advance care planning with the patient and family covering any implications relating to the legal responsibilities of the family caregiver(s).

Guideline 5. Recognise the family caregiver as an important source of information about the patient. Gather information from the family caregiver about his or her experience as a support person for the patient, including any information (where pertinent) regarding the patient believed possibly to be important for the health care professional team to know about.

Guideline 6. Explain to the family caregiver(s) what services and resources can be provided by the palliative care service so that realistic expectations are established.

Part 2: Assessing Need and Establishing a Plan of Care

Guideline 7. Whenever possible, convene a family meeting/case conference, including the patient if practicable.

Guideline 8. Conduct a needs assessment with the family caregiver(s). This should include psychological and physical health, social, spiritual, cultural, financial, and practical elements.

Guideline 9. Once the family caregiver(s)' needs are assessed, develop a plan of action with involvement from the family caregiver(s). Initiate the appropriate interventions as pertinent.

Guideline 10. Based on discussion with the family caregiver(s), determine the current state of and risk for poor psychological health and/or prolonged grief, and plan relevant intervention(s).

Part 3: Preparing for Death

Guideline 11. When appropriate, assist the family caregiver(s) in how to recognise signs that death may be imminent and the potential implications for the patient's care requirements.

Guideline 12. When death appears imminent ensure the family caregiver(s) are aware and assess preparedness for death.

Guideline 13. Confirm with the family caregiver(s) the type of support they may desire in the lead-up to death (e.g. last hours, days) and/or immediately after.

Guideline 14. The interdisciplinary team identifies a means of communicating with the family caregiver(s) to determine short-term and long-term post-death responses. Potential external bereavement support services are identified if required.

Part 4: Bereavement Support

Guideline 15. Relevant members of the interdisciplinary team are advised of the patient's death in a timely fashion.

Guideline 16. As soon as practicable after the patient's death, a member of the interdisciplinary team should contact

the family caregiver(s) to offer condolences and respond to queries. If death occurred at home, assess the need for a home visit.

Guideline 17. Develop a preliminary bereavement care plan based on the needs of the family caregiver(s), the predeath risk assessment, and the circumstances of the death (e.g. unexpected or traumatic).

Guideline 18. Contact the family caregiver(s) and other family members (as appropriate) to assess needs at three to six weeks post-death and adapt bereavement care plan accordingly.

Guideline 19. Conduct a follow-up assessment of the family caregiver(s) and other family members (if appropriate) six months post-death.

Guideline 20. Following the death of a patient, the interdisciplinary team should have a discussion (at an appropriate time) about the quality of care provided to the patient and family caregiver(s) and the nature of the death.

8.6 Gold Standard Framework (GSF)

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In terms of identifying patients at the end of life (and potentially their carers) the GSF Prognostic Indicator Guidance (PIG) and the National GSF Centre's guidance for clinicians supports earlier recognition of patients nearing the end of life. By identifying people who are in their last year of life clinically, GPs can then ensure their patients are more likely to receive high quality end of life care, have fewer emergency admissions to hospital and have a good death in the place of their choosing (Davidson and Gentry 2013). This campaign is hosted by the Dying Matters Coalition, working alongside Macmillan, the Royal College of General Practitioners and others to ensure that GPs' have the information and resources they need to support a good death. The PIG is endorsed by NICE, and QOF guidance 2011/2012. It also links to the Next Stage GSF Training Programme for general practices.

This campaign aims to enhance GPs' ability to:

- Identify patients with a year or less to live
- Initiate conversations about end of life care
- Put end of life care plans in place

The RCGP has developed the Gold Standards Framework Identification Toolkit to help identify terminally ill patients. Not only does it boost the chances of early identification, it can help determine what stage the patient is at through the prognostic indicator guidance (PDF) tool. The tool can be used by individual clinicians or by multi-disciplinary teams to judge whether patients are entering the dying phase of their lives. If this is the case, a discussion should be initiated with patients (and potentially carers) about their wishes. The GSF Prognostic Indicator Guidance also has details of clinical indicators by condition and these will be further explored in phase 3 of this scan (GSF 2011). This links to the "Find your 1% campaign" headed by Dying Matters (see page 104).

http://www.goldstandardsframework.org.uk/cdcontent/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf

8.7 NICE quality standards for families, carers and patients with advanced progressive, incurable conditions (QS13)

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http://www.nice.org.uk/guidance/qs13/chapter/Introduction-and-overview

These set out markers of high-quality care for adults aged 18 years and older with advanced, progressive, incurable conditions; adults who may die within 12 months; and those with life-threatening acute conditions. It also covers support for the families and carers of people in these groups. In addition to physical symptoms such as pain, breathlessness, nausea and increasing fatigue, people who are approaching the EoL may also experience anxiety, depression, social and spiritual difficulties. The proper management of these issues requires effective and collaborative, multidisciplinary working within and between generalist and specialist teams, whether the person is at home, in hospital or elsewhere. Information about people approaching the end of life, and about their needs and preferences, is not always captured or shared effectively between different services involved in their care, including out of hours and ambulance services. Carers experience a range of problems during EoL care. Their needs before, during and after the person's death should be addressed.

From a list of statements, some refer specifically to families and carers, these are outlined below.

The following statements contained in these guidelines relate specifically to carers and EoL care.

Statement 1 People approaching the EoL are identified in a timely way.

Statement 2. People approaching the EoL and their families and carers are communicated with, and offered information, in an accessible and sensitive way in response to their needs and preferences.

Outcome: People approaching the EoL and their families and carers feel sufficiently informed about what they wish to know and supported to make decisions about their care.

Statement 7. Families and carers of people approaching the EoL are offered comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences.

Statement 13. Families and carers of people who have died receive timely verification and certification of the death.

Statement 15. Health and social care workers have the knowledge, skills and attitudes necessary to be competent to provide high-quality care and support for people approaching the EoL and their families and carers.

Statement 16. Generalist and specialist services providing care for people approaching the EoL and their families and carers have a multidisciplinary workforce sufficient in number and skill mix to provide high-quality care and support

8.8 Palliative and EoL care for BAME groups in the UK. Demographic profile and the current state of palliative and EoL care provision

This report examines palliative and EoL care for BAME groups in the UK and recommends that the focus of EoLcare now needs to shift from care for those with terminal cancer, to care for everyone from all backgrounds and all terminal illnesses. The impact ethnic and cultural differences have on all aspects of health and the take up of health care services is acknowledged, evidence showing that BAME groups are low users of EoL care services. BAME groups will soon represent a significant proportion of the over 65's in our communities and ensuring that they receive end of life care and support is a challenge. Misunderstandings, mistrust and a lack of cultural sensitivity on the part of providers of services have contributed to this low uptake. Increased communication with these groups could begin to address that some BAME groups do feel able to access end of life care and others do not engage with services. Training for HCPs will enable them to provide appropriate care to people from the different ethnic, cultural and religious background within their locality. This may require them to make significant changes to the way in which they have traditionally worked with people and their families. Policy makers and commissioners will also wish to understand the needs of their BAME populations and ensure that they deliver health and social care which is available on an equitable basis.

Early outputs from this project are reaching a better understanding of the needs of individual ethnic and cultural groups and of the types of services which will best meet their end of life care needs. Other areas will be researched and generate working partnerships between service providers and local communities so that their needs are responded to in a sensitive fashion. (Calanzani, Koffman et al. 2013).

8.9 Caring Together

The document "Caring Together. The Carers Strategy for Scotland" has addressed BAME and LGBT carers (and indeed disabled carers) setting out key actions to improve support to carers over the next five years. These are as follows:

- The Equality Act 2010 is intended to protect the rights of individuals and advance equality of opportunity for all; to update, simplify and strengthen the previous legislation; and to deliver a simple, modern and accessible framework of discrimination law which protects individuals from unfair treatment and promotes a fair and more equal society
- Ensuring equalities in race or ethnicity, disability, gender or sexual orientation, age or religion means ensuring opportunity for all carers to access suitable resources and support
- Support needs to be delivered in a sensitive way. For example, carer training might be delivered to BAME female carers in their own right. In relation to gender issues, professionals have to recognise that daughters may not wish to carry out personal care for their fathers
- Health and social care professionals need to be sensitive to different forms of caring relationships.
- Culturally competent services should be delivered and all those involved in end of life care should be culturally competent for all minority groups (Government 2010)

8.10 Route to success: achieving quality for lesbian, gay, bisexual and transsexual people.

This National EoL Care Programme guide offers guidance and advice for those working with LGBT people, and for LGBT people themselves, whether giving or receiving end of life care.

In the UK, accurate numbers of people who identify themselves as LGBT are hard to establish. Official figures vary between 750,000 and 3.6 million. In 2009, the number of people who had sought gender reassignment treatment was estimated at 12,500, with the expectation that this figure will grow as more transgender people feel able to seek increasingly available support.

LGBT people are at risk of not receiving high-quality EoL care services, with many facing problems in terms of being treated with dignity and respect. Having a LGBT identity can sometimes directly impact on the experience of end-of-life care. The National EoL Care Programme has therefore developed the document above following consultation with stakeholders at a series of discussion groups held around the country, this offers guidance and advice for those working with LGBT people, and for LGBT people themselves, whether giving or receiving EoL care. The guide aims to:

- Encourage LGBT people to be confident in being open about their relationships and needs
- Guide organisations and people within them to have an LGBT-friendly culture
- Highlight constructive key messages for everyone to act upon

Following the six steps of the EoL Care Pathway each section in this document identifies issues to consider and links them to practitioner and staff roles. Case studies are used to highlight good practice and key recommendations for future practice are included.

www.endoflifecare.nhs.uk/search-resources/resources-search/publications/the-route-to-success-in-end-of-life-care-%E2%80%93-achieving-quality-for-lesbian,-gay,-bisexual-and-transgender-people.aspx

Section 9. Mandatory support for carers

Some aspects of the legislation below have succeeded in moving beyond 'enabling' legislation and policies, and have given to carers limited but enforceable rights, placing new statutory obligations on local authorities, and other organisations (Yeandle and Fry 2010).

9.1 The Equality Act 2010

The Equality Act 2010 brings together a number of acts and regulations, which formed the basis of anti-discrimination law in Great Britain. It requires equal treatment in access to employment as well as private and public services, regardless of the protected characteristics of age, disability, gender reassignment, marriage and civil partnership, race, religion or belief, sex, and sexual orientation.

The Equality Act provides protection for carers where they are provided with a worse service than someone who is not caring for a disabled person. It also includes protection where carers are discouraged or prevented from using a service because they are caring for a disabled person recognising the vital role that carers play and the disadvantage this role can bring with it. This, has strengthened carers protection against discrimination both in the workplace and when accessing services. The Government Equalities Office and Citizens Advice have published a quick-start guide on how the new law can help carers. The Equality and Human Rights Commission has also published wide-ranging guidance on the new law.

http://www.legislation.gov.uk/ukpga/2010/15/pdfs/ukpga_20100015_en.pdf

9.2 Care Act 2014 - support for local authorities and care providers

The Care Act 2014 strengthens the rights and recognition of carers in the social care system, and will come into effect in April 2015. Carers now have new rights and this act means that any carer who appears to have a need for support should be offered an assessment by the local authority. From April 2015, carers are entitled to an assessment by Social Services no matter what the level of need is, the amount of care provided or the financial means. Carers can have an assessment whether or not the person they are caring for has had a community care assessment/needs assessment or if they have been considered not to be eligible for support. The assessment will look at how caring affects the life of the carer, including health issues and whether they are able or willing to carry on caring. It examines physical, mental and emotional needs relating to your workplace, your education, maintaining relationships, and social activities. Following the assessment, social services will decide if a carer is eligible for services to be provided to the carer or to the person cared for to reduce the impact of caring. The decision about whether social services pay for services to support a carer will depend on their financial situation (if services are provided to them) or on the financial situation of the person they are caring for (if services are provided to them as a result of your assessment). At a minimum, social services must provide all carers – including those not considered eligible for support – with information and advice.

http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted

9.3 Care Act 2015

The rights of carers to be assessed have been strengthened with the introduction of this updated Care Act in April 2015. Within the act there is a new single duty for local authorities to undertake a carer's assessment based on whether a carer may appear to have needs for support, either currently or in the future. Carers will be entitled to services and support where their needs meet the national eligibility criteria. Local authorities have a mandatory requirement to ensure carers and patients are safe at home. The Social Care Institute for Excellence (SCIE) web pages take HCPs and carers through these acts and there are presentations available to download.

http://www.scie.org.uk/care-act-2014/carersuk.org/careact

Section 10. Health care professional training and guidance

Doctors, nurses, and other health professionals often do not have sufficient training to meet the demands of EoL care – of the patient, or their families. They can find this work very stressful and emotionally taxing (Pattison, Carr et al. 2013). The importance of a well trained workforce to support the needs of those approaching the end of their life and their carers is readily acknowledged. However, relatively few healthcare professionals are specifically trained to manage palliative and end of life care. Access to suitable education is often patchy and many health and social care providers have difficulty accessing relevant education and training (Smith and Brown 2012).

Although many caregivers acknowledge positive aspects associated with the role, a considerable proportion will experience poor psychological, social, financial, spiritual, and physical well-being and some will suffer from complicated grief. Thus many people have unmet needs and would like more information, preparation, and support to assist them in the caregiving role. There is a shortage of evidence-based strategies to guide health professionals in providing optimal support while the caregiver is providing care and after the patient's death. There is evidence that implementing clinical guidelines, protocols, and tools facilitates improvements in care. Examples include timely referrals to palliative care, reduced emergency department admissions, decreased length of stay in hospital, and an increase in the proportion of deaths at home or in a non-acute care facility (Hudson, Remedios et al. 2012). Nurses have limited preparation in giving information to patients and their carers about this aspect of their work and they urgently need carefully tailored training in this aspect of their work (Griffiths, Ewing et al. 2015).

10.1 Leadership alliance for the care of dying people

Engagement with patients, families, carers and professionals: proposed advice for health and social care practitioners involved in looking after people in the last days of life.

NHS England, 2013 Web publication
http://www.england.nhs.uk/wp-content/uploads/2013/12/lacdp-engage.pdf

Associated documentation:
https://www.engage.england.nhs.uk/consultation/care-dying-ppl-engage/consul

10.2 Wirral EoL care project

The ‘Core Competencies for EoL Care’ were used to inform a project for the Wirral domiciliary workforce in 2010/11. The project was funded through the regional multi-professional education and training fund supported by the North West EoLC operational group (NHS and Local Authorities).

The Wirral project was a partnership with Wirral Metropolitan College (WMC), Wirral Council Department of Adult Social Services, NHS North West Cancer Network, Wirral NHS EoL Team, social care employers and specialist EoL multi-disciplinary teams. It was recognised that there are significant unmet training needs and the aim of the project was to improve the knowledge, skills and behaviours of workers and improving communication between domiciliary care agencies and primary care services in EoL service to the Wirral community.

The project produced a two day course ‘Introductions to the Principles of EoL Care’. WMC developed, delivered and evaluated the programme delivery, impact and sharing of good practice across the North West. 300 plus domiciliary care staff have completed the training, including workers from the Merseyside Chinese Community Development Association (MCCDA). Materials were translated into Cantonese and interpreters were used during the delivery of the programme.

The project included training for social workers and assessment support officers. Evaluation has shown continuous quality improvement and feedback has been extremely positive including increased confidence, skills and knowledge. Service user case studies highlighted the difference training has made to the quality of care and support to the family at a most vital time.

The project was showcased at the NW EoLC Conference in September 2011 to all NW LA’s and NHS EoLC Leads.

Contact:
Jo Williams,
jowilliams@wirral.gov.uk

10.3 E-learning, web resources and tele healthcare

10.3.1 Supporting carers

The Supporting Carers in General Practice e-learning programme has been developed for primary care professionals, to help them to support people who care for others. It has been developed by the Royal College of General Practitioners, in partnership with the Princess Royal Trust for Carers and with support from The Children's Society. The programme contains six e-learning sessions:

- Supporting those who provide care for other people
- Identifying carers
- Organising your practice to support carers
- Supporting young carers
- Support for older people and their carers
- Supporting the carers of people with challenging problems

E-LfH content is free of charge to those who work within the NHS. Please note that you will require an NHS or equivalent email address to register. The Supporting Carers in General Practice programme is also available to NHS healthcare staff in England via the National Learning Management System (NLMS). The NLMS is an e-learning platform fully integrated with the Electronic Staff Record which means learning can be recorded against your portable employee record. Please contact your local learning and development department about accessing this content via the NLMS. Further details are available here: National Learning Management System Project.

http://www.e-lfh.org.uk/programmes/supporting-carers-in-general-practice/

10.3.2 Developing end of life care practice

A guide to workforce development to support social care and health workers to apply the common core principles and competences for end of life care:

http://www.nhsiq.nhs.uk/resource-search/publications/

10.3.3 General End of Life modules

E-ELCA e-learning. Free to access for health and social care staff and includes over 150 modules covering advance care planning, assessment, communications skills, symptom management, integrated learning, social care, bereavement and spirituality.

www.e-lfh.org.uk/projects/e-elca/index.html

10.3.4 LGBT

There is also a need for HCPs to be educated on LGBT issues and communities in their locality. The LBGT toolkit from Kent County Council in 2011 is a staff toolkit to promote and embed good practice in residential and nursing care when working with LGBT people in residential and nursing care.

http://www.kent.gov.uk/adult_social_services/your_social_services/services_and_support/older_people/unable_to_live_at_home/residential_and_nursing_care.aspx

10.3.5 Tele health care

City and Guilds has a project related to Information Communication Technology (ICT) and care. This is an accredited course for care workers to learn how to assign appropriate telecare packages to clients in needs of them. The course, the "Certificate in Supporting the Users of Assistive Technology", is in a very early stage of development, and so far has had little take-up. This was attributed to the fact that tele health care projects have yet to be mainstreamed in the career market for care workers, with such qualifications often regarded as "luxuries" rather than essential. Nevertheless City and Guilds is committed to delivering this course and has high hopes for its future (Yeandle and Fry 2010).

10.4 Written resources for HCPs

10.4.1 Care of the dying: A pathway to excellence (Edited by John Ellershaw and Susie Wilkinson)

Even for the most experienced healthcare professional, managing the last few days of someone's life can be difficult. This book provides guidelines for the care of the dying based on the Liverpool Integrated Care Pathway for the Dying Patient (LCP). Developed at a hospice, the information can be disseminated and adapted to fit different settings such as hospitals and nursing homes. The LCP is a multiprofessional document that incorporates evidence-based practice and appropriate guidelines related to care of the dying. It provides a template which describes the process of care which is generally delivered in a clinical situation and incorporates the expected outcome of care delivery. The LCP replaces all other documentation in this phase of care. Care pathways can provide a potentially powerful aid to professionals involved in palliative care. Basic principles of treatment are translated into daily practice, including bedside documentation systems, policies and procedures, standards of practice, continuing education and quality improvement programmes. This book also includes chapters on symptom control, ethical issues, communication skills, and spiritual care written by experts in the field which underpin the use of the LCP.

Care of the Dying Second Edition will prove invaluable to all healthcare professionals involved in the care of the dying patient, organisations and Trusts who want to develop demonstrable measures and outcomes of care (Ellershaw and Wilkinson 2011).

10.4.2 Family carers in palliative care: a guide for health and social care professionals (Edited by Peter Hudson and Shelia Payne)

The book has an international and multidisciplinary focus. This book aims to provide a practical guide to family carer assessment and support and also explores key sociological, policy and research issues. Family carers often play a major role in the care of their dying relative and are prone to negative physical, social, financial and psychological outcomes. The philosophy and practice of palliative care includes not just the patient as the 'unit of care', but also the family. Consequently health and social care professionals are required to support the patient's family during their relative's illness and also during bereavement, but can find this type of support challenging (Hudson and Payne 2009).

An independent review of this book is in the appendices section,

10.4.3 Skills for care and skills for health: Common core principles and competences for social care and health workers working with people at the end of life (2014)

This booklet is aimed at HCPs who are not specialists in EoL care. It sets out the principles for working with adults at the end of their life, and describes the underpinning competences, knowledge and values they should have. The principles refer to carers[23] as well as patients and are as follows:

- Care and support is planned and delivered in a person-centred way, with the person’s priorities,including spiritual, emotional and cultural needs, guiding all decisions and actions
- Communication is straightforward, appropriate and timely, and is delivered sensitively, taking account of the circumstances, needs and abilities of the person and their carers. Communication reflects an understanding of, and respect for, the person’s cultural and spiritual needs
- EoL care is provided through integrated working, with practitioners collaborating to ensure seamless care and support at the point of delivery. Needs are met in ways that are appropriate to the person, rather than being service-led. Workers maintain ongoing communication so that care and support is properly co-ordinated and responsive to changing circumstances and priorities.
- Good, clear and straightforward information is provided to the person and their carers
- Regular reviews and effective communication ensure that care and support is responsive to the needs and changing circumstances of people at the end of life, and their carers. Forward planning, including advance care planning, facilitates well-coordinated, planned and organised care and support
- The needs and rights of carers are recognised and acted upon. Carers are offered support both while caring, and during bereavement. Employers recognise the ways in which workers are affected while caring for someone who is dying, and provide appropriate guidance and support

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[23] *‘Carer’ is used to refer to family and friends who provide social care support, as distinct from social care, health or community workers or volunteers.*

- Employers provide appropriate learning and development opportunities for workers to ensure that they are properly equipped to work with people at the end of life. Workers are encouraged to take responsibility for their own learning

These are expanded upon in the booklet and constitute a good resource for HCPs caring for people and their families at the end of their life. Core competences, underpinning values and knowledge are also described:

- Communication Assessment and care planning
- Advance care planning
- Symptom management, maintaining comfort and wellbeing

http://www.skillsforcare.org.uk/Skills/End-of-life-care/End-of-life-care.aspx

10.4.3 NCPC Six steps to improve support in bereavement

This is a general, brief look in a very useful 10 page document, at what actions could be taken to improve bereavement support at a national, regional and local level. With regards to the MHMC programme the following sections are useful:

Section 3: Clarity about who is responsible locally for commissioning and providing bereavement support, with better coordination and information about services.

Section 4: Training in bereavement for all those coming into contact with bereaved people, at a level appropriate to their role.

Section 6: More compassionate communities where everyone knows enough about grief to play their part in supporting people around a death

http://dyingmatters.org/sites/default/files/Life%20After%20Death%20FINAL(1).pdf

10.5 Carer support related current guidelines for health professionals

10.5.1 Evidence based clinical practice guidelines

These evidence based guidelines are from the Centre for Palliative Care in Australia and on various topics which are listed below. They are endorsed by a number of Australian organisations, by St Christopher's Hospice, London and the International Observatory of End of Life Care in the United Kingdom.

1. EMRPCC: End of life care: Management of respiratory secretions (2013)
2. EMRPCC: Opioid conversion ratios - Guide to practice 2013 v. 2 (Nov 2014)
3. MRPCC: Syringe driver drug compatibilities - Practice guidelines 2013 v. 2 (Nov 2014)
4. Palliative care nurse practitioner - Symptom assessment guide (2011)
5. Palliative care nurse practitioner candidate - Clinical competencies (2011)
6. EOLRSF: Noisy breathing at end of life (2013)

Copyright 2010 but can be downloaded for use.

10.5.2 Multidisciplinary clinical practice guidelines. Family meetings in palliative care

Support for family carers is a core function of palliative care service provision. Service providers therefore, have a responsibility to offer family meetings based on need. These provide an opportunity to enhance the quality of care provided to palliative care patients and their family carers.

Family meetings can be a useful way to assist patients and family members to clarify goals of care, consider site of care options, and to share information. They also offer facilitation for the airing and resolution of family conflict (pc, TA, 13/4/2015). They provide a safe environment where issues and questions can be raised and appropriate strategies agreed upon. They are not only potentially valuable for patients and family carers; they also make clear what services can and cannot offer. Such meetings provide an opportunity to triage priority issues and a way to make referrals to other health professionals or other institutions early in the care planning phase. Rather than reaching a 'crisis' situations, family meetings represent a preventative approach where issues are anticipated (proaction) before they become major dilemmas (reaction). HCP's facilitating family meetings require appropriate skills in group work, therapeutic communication and palliative care. Pre-planning for the actual meeting is imperative and there should be a comprehensive follow up after the meeting. Pre and post-Family Meeting Primary Family Carer Questionnaires are available for evaluation purposes. Appropriate resources should be available to patients and family members who attend the meeting in order to complement verbal information (e.g. brochures about services available, carer guidebooks, treatment and drug information, etc). These clinical guidelines offer a very detailed and comprehensive framework for preparing, conducting and evaluating family meetings [24].

A multi-media resource, conducting family meetings: a resource for health professionals working in cancer and palliative care demonstrates how to use these guidelines.

http://centreforpallcare.org/assets/uploads/Family_Meetings_in_PC_Multidisciplinary_Clinical_Practice_Guidelines.pdf.

www.pallcare.unimelb.edu.au

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[24] *The guidelines are evidence based and endorsed by: Carers Australia; Carers Victoria; Palliative Care Australia; Palliative Care Victoria; Australian Centre for Grief and Bereavement; St Christopher's Hospice; London (UK); International Observatory of End of Life Care (UK); Beyond Blue.*

Section 11. Recommendations for training, supporting and educating carers

Historical national training initiatives for carers which involved formal qualifications , such as *Learning for Living*, City & Guilds, were developed in 2002-2005 as part of the EU-funded 'Action for Carers and Employment' project led by Carers UK . *Learning for Living* operated as an on-line learning resource through which carers could obtain a Certificate in Personal Development and Learning for Unpaid Carers, a qualification accredited at level two within the National Qualifications Framework 2 (Yeandle and Starr 2007).

Looking After Me, a course within the DoH-funded Expert Patient Programme was designed for adults looking after someone living with a long-term health condition or disability aimed to promote self-help and the sharing of experience and expertise among carers (Hare and Newbronner 2005) cited in (Yeandle and Wigfield 2011).

There were also programmes of support for carers in Scotland - with some operating at the local level in England, mainly small projects operating through local carers' organisations such as those linked to the Princess Royal Trust for Carers (PRTC) and some of these still run today. Carer support programmes including one run by the Alzheimer's' Society for carers of dementia sufferers; a programme for black and minority ethnic (BAME) carers; and for carers in rural communities by Carers Scotland, (Carers 2009) cited in (Yeandle and Wigfield 2011). The Scottish Government still support BAME, LGBT and disabled carers. (Government 2010).

An early DoH small 'mapping exercise' explores what training provision for carers was already available in England. This showed that there were at least 176 organisations providing such training in England in Spring 2006. Among these, 25% were carers' organisations, 24% were local authorities, 21% were NHS bodies, and 17% were other local charities. There was also some provision available through national carers' organisations and other charities (Clarke and Riley 2006).

A systematic review of UK interventions and services for carers undertaken more recently reported positive findings about carer education and training programmes. Despite some evidence that skills may not be maintained over time[25], most studies reported consistently positive outcomes for carers in terms of developing new knowledge and skills and building confidence (Victor 2009). Interventions should be 'active and targeted' rather than being 'passive and generic', these will increase carers' knowledge and abilities (Parker, Arksey et al. 2010)

As discussed above the Commission into the Future of Hospice Care in the UK suggested the following as vital for carers:

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[25] *This may not be so important given the context of end of life caring, the point being that carers have the specific skills for the duration of the time they require them and which may not be needed anymore following a bereavment.*

- Strategies for safe moving, lifting and handling of the patient.
- Information resources on disease process, trajectory and prognosis.
- Information on how to provide specific care tasks, equipment and medication.
- Information about the dying process and symptom management in a timely way
- Access to welfare or benefits advice.

And the EAPC endorses all of these points adding in medical education, including on medication, nutrition and symptom control; and education on how to offer emotional support to the patient. Such interventions have to be timely however and there is debate about the best time to provide them. In addition, support that takes carers out of the home may sometimes be problematic for them to attend (EAPC 2010).

The following section offers recommendations for designing, developing and running an educational programme for carers of people at the end of their life. One UK organisation has specifically addressed EoL Care and this organisation has offered to discuss this with the MHMC project team. In spite of there being a dearth of structured education courses in terms of many elements of the MHMC programme proposals, notably in the areas of skin and wound care, administering medicines and injecting (only one has been identified) some of the MHMC proposals are addressed in this EBS. Identifying and preparing carers has been identified as a major consideration as has training and equipment for the physical tasks of moving and handling. Provision of BAME and LGBT carers is beginning to be addressed in parts of the UK where, at one time, this was not an issue. CwC badged programmes are being run in various UK locations.

Recommendations for gaps identified in the MHMC proposed curriculum have been suggested by the author of this EBS. Implementing these will meet most guidelines, strategies and recommendations cited above in the various sections of this report. Key practical and logistical points have been suggested which need to be addressed when designing an educational programme.

11.1 Identifying carers

This is the first step towards engaging carers in their role and in their accepting information and support. Earlier identification and referral of carers is needed – the last few days/hours of the patient's life is too late to introduce carer support and any help at this point is unlikely to make a real difference. Carers should be identified early and referred for support before crises are reached and time is running out. In cases where there is no statutory input because patients are refusing to accept help/input from any statutory services, it is difficult, in turn, for carers to access support including bereavement support, or be referred for support in their own right to statutory services. However, this can be put in place even if the level of need in their patient is deemed 'too low' for statutory eligibility criteria.

As discussed above, some carers are not easily identified. It is the case however, that carers are more likely to have seen their GP recently than any other support professional. It is vital for General practitioners and their primary care teams to know how to identify and support carers in order to maintain the health of the carer, and to facilitate the care giving situation

http://www.e-lfh.org.uk/programmes/supporting-carers-in-general-practice/

11.2 Awareness raising in primary care - Dying Matters pilot project

11.2.1 Evaluation of the Dying Matters GP pilot project

Many GPs find it difficult to find a way into a conversation about dying with patients. Even though patients may drop cues into a consultation GPs sometimes choose not to follow up on these. They find it difficult to bring up these issues and some see it as risky to introduce this topic when not initiated by patients. In 2010, the Dying Matters Coalition undertook a pilot project raising awareness of dying death and bereavement amongst GPs to try and allow patients to have access to good clinical care, talk about dying and their choices. There was an evaluation of this project in 2011**:**

http://www.dyingmatters.org/sites/default/files/user/documents/Resources/Dying_Matters_GP_Pilot_Evaluation-final.pdf

11.2.3 The "Find your 1% campaign"

Linked to the two initiatives above, this campaign aims to support GPs and other health and social care staff in identifying the 1% of people who are likely to be in their last 12 months of life (and potentially, their carers), in order to talk about, plan for and meet their end of life care needs and preferences. Dying Matters heads this initiative and their website offers advice and pointers to GPs about identifying patients in their last year of life (usually about 1% of patients). In addition to other issues, this will allow both the patient and their carers have time to deal with this news and realign their priorities.

Supporting GPs within Pennine Care NHS Foundation Trusts geographical area to do this may identify or alert those that care for others so that they can be offered timely support and education.

The issues of formally identifying patients for palliative care have been explored by three Scottish NHS Boards with GP practices. For those with non-malignant conditions (most palliative care services and documentation being aimed towards cancer patients) only around 20% had any palliative care documented. This was because current guidelines were not useful to GPs and they are reluctant to discuss palliative care overtly with patients early in their illness. Their inclusion on the palliative care register was seen as beneficial by district nurses and, if formally identified these patients (and their carers) would be more likely to benefit from coordinated care and may be more likely to die at home is this was their wish.

Most patients with advanced progressive illnesses, especially those with non-malignant disease, are not being formally identified for a palliative care approach before they die. Those identified are more likely to benefit from coordinated care and may be more likely to die at home (Harrison, Cavers et al. 2012).

http://www.scie-socialcareonline.org.uk/are-uk-primary-care-teams-formally-identifying-patients-for-palliative-care-before-they- die/r /a1 CG 0000000GcadMAC

11.2.4 The "End of Life Care for All (e-ELCA) Supporting carers in general practice"

This e-programme for primary care professional staff has e-learning sessions one of which is identifying carers.

http://www.e-lfh.org.uk/programmes/supporting-carers-in-general-practice/

11.3 Preparing carers: evidence-based strategies that prepare family caregivers for supporting palliative care patients - The Melbourne Family Support Programme (FSP).

Preparing carers for their role is important. Carers consistently report that communication and information related to EoL care is inadequate (Hudson and Aranda 2013). In addition to information that prepares them for supporting a dying relative, including how to keep them comfortable, practical care needs, family carers require additional strategies to minimise their psychological burden (Hudson 2013).

The Melbourne FSP[26] represents a rationale and a conceptual framework for their programme which explored healthcare-led psycho-educational mechanisms aiming to increase family caregivers' sense of preparedness for their role bolster their positive emotions reduce their unmet needs reduce their psychological distress

The theoretical framework for guiding the Melbourne FSP was based on a transactional model of stress and coping. This model was identified in the initial scoping scan and proposes that the various responses related to EoL issues from patients and family caregivers can be understood from a psychological perspective based on this model. That is, caregivers appraise their situation to determine the potential impact of a potentially stressful event. The more prepared and capable they are, or the greater the number of resources at their disposal to manage an

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[26] *The Centre for Palliative Care, St Vincent's Hospital and Collaborative Centre of The University of Melbourne, Australia.*

event, (including being in possession of adequate information) to prepare them for their role, the more likely carer can adapt and cope with their role.

Resources also include; fewer unmet needs and focusing on positive aspects in order to minimise psychological distress. Strategies that targeted these domains were core to the Melbourne FSP, the aim being to develop evidence based strategies (and associated resources) that focus on promoting the psychosocial well-being of primary family caregivers of patients receiving palliative care.

Pilot work comprised four interventions involving healthcare professional-led, direct interaction with family caregivers in both one-to-one and group formats, conducted in either the home or inpatient/hospice setting. Results from these included the development of a guidebook on preparing family caregivers for the role of supporting a relative/friend with a palliative care diagnosis. A critical literature review of supportive interventions for family caregivers confirmed that new strategies needed to be developed and RCTs of psycho-educational interventions a priority. These should be developed pragmatically and take into account, family related challenges, health system barriers and communication barriers. As previously identified a pilot RCT has been undertaken, which showed that carers who received this type of intervention had a more positive caregiver experience (Hudson, Thomas et al. 2009). Insights from the pilot work channelled the work into developing evidence based strategies and resources that focussed on promoting the psychosocial well-being of primary family caregivers of patients receiving palliative care using healthcare-led psycho-educational mechanisms to:

- increase family caregivers’ sense of preparedness for their role
- bolster their positive emotions
- reduce their unmet needs
- reduce their psychological distress (Hudson and Aranda 2013)

Being prepared for caring was very important for family caregivers

Evaluated psycho-educational programmes included:

- group sessions three times a week to prepare carers for the role of supporting a relative with advanced cancer at home, (Hudson, Thomas et al. 2009)
- the meaning of Friday afternoon tea for informal caregivers on a palliative care unit. A support group for carers of patients in a palliative care unit gave them time to talk to staff, feel supported and cared for, gave them a sense of their community and a positive distraction (Parsons and Anderson 2009)

- an eight-week bereavement support group in a hospital setting suggested that men and women respond differently to bereavement groups. Bereaved individuals with high anger and tension may require interventions addressing their particular needs, with a focus on acceptance of negative emotions (Maruyama and Atencio 2008)

11.4 Assessing carers

Assessing carers is a priority. Ensuring that family caregivers' needs are appropriately assessed is one of the top ten quality markers for EoL care (DH 2009). The unpredictability of caring for a person at the end of life is an important factor when determining what carers need because the condition of a patient who is receiving palliative care can alter quickly (EAPC 2010).

With an ageing population, the UK will need more care from families and friends in the future. This is an issue that will touch everyone's life at some point. The Carers Trust[27] state that carers are the largest source of care and support in each area of the UK and it is everyone's interest that they are supported. Taking on a caring role can mean the following:

- facing a life of poverty, isolation, frustration, ill health and depression
- relinquishing employment and their income, future employment and pension rights
- juggling work and caring responsibilities
- caring alone and not knowing about carer entitlements

All carers share some basic needs:

- services that recognise their individual and changing needs throughout their caring journey.
- access to information, financial support and breaks in caring
- respect and recognition from HCPs in order for them to care safely and maintain their own physical and mental health and well-being
- improved support for the person being cared for can make their role more manageable.
- post-caring, carers may need support to rebuild a life of their own and reconnect with education, work or a social life

http://www.carers.org/merger

Family carers should not have to wait until the patient is at home/ in the late stages, to receive formal guidance about their role. Given palliative care standards and carer charters continue to mandate carer support based on needs assessments, suitable funding will be required to uphold these policy requirements in order for HCPs to be able to respond to them.

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[27] *Crossroads Care and The Princess Royal Trust for Carers have merged to form the leading carers charity, Carers Trust*

The scenario of discovering, following an assessment from a health professional, that a family carer lacks the preparation and skill set to support a dying relative, and then to find there are no resources for an appropriate response however, is unethical and should be avoided. This could exacerbate the impact of caring for a family member and could significantly influence their mental health (Hudson 2009).

Carers should, therefore, be altered to their statutory right to an assessment and ensure that the assessment is followed by a written care plan that is implemented. It should be ensured that:

- carers have a named professional who can assist them in accessing health and social care services, equipment and support
- there is a single point of contact for carers through which they can arrange a home-based assessment for home-based equipment by a qualified professional, such as an occupational therapist, and be trained to use it as necessary
- carers have direct access to advice on financial planning, available benefits and how to maximise household income (SCIE 2013)

It should be remembered that carers:

- should receive evidence-based support from health professionals as per national and international policies and standards
- are receiving support which is neither systematic nor fully evidence based
- are prone to physical and psychological morbidity
- are responsible for numerous tasks, such as symptom management
- report unmet needs (typically aligned with lack of information about their role)
- have needs equal to and/or greater than the patients' needs
- have very limited first-hand exposure to death and dying
- are often excluded from information and care planning and, consequently, feel underprepared for their role
- have the potential (with suitable support) to gain positive outcomes from their experience.
- are pivotal to achieving 'successful' home care (where most people prefer to die)
- make a substantial economic contribution to Healthcare
- may significantly enhance the patients' well-being when their role is well supported (Hudson and Payne 2009)

There remains, however, a need for robust, short and acceptable theoretically driven, assessment tools for assessing carers' needs that are available to palliative care professionals for use in daily practice (EAPC 2010).

11.4.1 The Carer Support Needs Assessment Tool (CSNAT)

Academics at the University of Manchester and at the University of Cambridge have received several grants in order to test this tool in various international contexts. In addition to those UK sites involved in a NIHR RfPB trial an additional 40 HHC services are committed to implementing the CSNAT in late 2013 which could go on to benefit 18,000 – 20,500 carers per year.

The Carer Support Needs Assessment Tools (CSNAT) is an evidence-based direct measure of carers' support needs in 14 domains. It is short, comprehensive and suitable for EoL care research and practice (Ewing, Brundle et al. 2013, Ewing, Grande et al. 2013). This tool has been developed with carers and extensively tested. It encompasses and assesses the physical, psychological, social, practical, financial, and spiritual support needs for family caregivers during EoL care emphasised by many international governments.

The CSNAT was used by practitioners for EoL care in a study in Australia, which explored carers' experiences of the measure in this context. In a three part evaluation, 233 carers provided feedback, nearly all of them finding the CSNAT assessment process straightforward and easy. Using the measure highlighted four key themes for carers:

(1) the practicality and usefulness of the systematic assessment
(2) their emotional responses and reflection on being a caregiver
(3) validation, reassurance, and empowerment of their role; and
(4) accessing support and how this was experienced

Thus, the CSNAT not only successfully identified care needs but also succeeded in engaging them in conversations related to their needs, priorities, and solutions (Aoun, Deas et al. 2015).

The CSNAT asks a carer whether they need more support with aspects of caring within 14 domains. They tick one of four boxes to give their answer for each domain, each covering a certain level of need ranging from no help to a lot more help needed. The 14 domains would be able to encompass needs relating to:

- Their understanding of a specific disease condition, its side effects, what is available to help them lift and handle their patient, personal care and concerns about medication issues
- Their personal needs related to respite care, mental health, physical health and spiritual needs and beliefs (this could encompass BAME and LGBT issues given the opportunity to engage in discussion about these)
- Day to day practical issues, financial, employment, legal issues and access to 24 hour help

The tool is freely available but copyrighted and it is recommended that the MHMC team and Pennine Care NHS Foundation Trust enter into discussions with the UoM about the use of this tool. Please see *http://csnat.org* for further information.

11.4.2 Physical assessment

Carers have been shown to neglect their own health and lifting a patient, for example, may cause back injuries and fatigue is common. A systematic review of the practical information needs of informal carers providing home-based cancer palliative/EoL care also highlighted unmet practical needs in terms of positioning and technical equipment (EAPC 2010).

This is a risk factor for carers and in order to increase high-quality care at home until the end of life, initiatives should be adopted by services and policy-makers that address important issues such as assessing and addressing such factors (Davidson and Gentry 2013). Courses run by The Princes Trust on moving and handling have been previously described and are run by physiotherapists. These may be worth examining and emulating. Should carers experience back problems, this could reduce their ability to care http://www.prtlcc.org.uk/en-us/courses/courses-movinghandling.aspx. This could be costly in terms of NHS care. Carers should be assessed for social care support, at the very least for respite and help with household tasks SCIE.

As described above, Wiltshire Council also offer courses on handling equipment, manual handling, moving and handling, moving and people handling, advanced handling and first aid for carers at various venues including memorial halls http://carersinwiltshire.co.uk/training/

The Norfolk organisation which is designing a bespoke EoL course invites occupational therapists to be present and contribute to sessions. This stimulates discussions around these kinds of needs, especially as the patients deteriorate and physical dependency increases (PC. TA13/4/2015).

Assessing the needs of carers and patients in relation to moving and handling should be a priority.

Any equipment or resources needed should be available.

Local authorities have an obligation to help carers avoid health and safety risks. They may run training courses on manual handling and may provide equipment to make caring for someone safer and easier. If they do not offer manual handling courses, carers can ask for a direct payment so they can pay for the course of their choice.

http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/mobility-problems-carers.aspx

11.4.3 Psychological assessment and support

A life-threatening diagnosis can have a greater negative psychological impact on family members than the patients themselves. Depression rates of between 12% and 59%, and anxiety rates of between 30% and 50% in caregivers have been reported. A recent study involving caregivers (n=300) soon after referral to specialist palliative care, identified that approximately half of them met the criteria for psychological distress (based on a validated screening instrument). Unfortunately, these high rates of psychological distress are typically under-recognised, and consequently, not addressed (Hudson and Arande, 2015).

To assess the mental health of carers would need considerable thought but is an imperative. Psychological support, counselling, stress management, relaxation and other techniques are needed to promote well-being and reduce anxiety and depression. Carers need help during the period of caring and afterwards, to prepare themselves for grief, loss and bereavement. Carers who were combining caring and paid employment may need support in returning to work (EAPC 2010).

Carers identify a range of psychological difficulties (including depression and anxiety, feelings of powerlessness and helplessness, low caregiver esteem), physical and emotional stress, and psychosocial difficulties. Intense, negative, conflicting and difficult emotions (fear, guilt, hopelessness, etc). Combined with feelings of inadequacy, insufficiency and uncertainty about their abilities, this can accelerate stress and burnout. Carers are also often extremely socially isolated, and may have little opportunity to engage with everyday normal life. As noted above some carers take on this role with reservations (Hudson and Aranda 2013).

Additionally, many carers are themselves elderly and frail and the caring role is often associated with sleep disturbance and fatigue. Physical frailty can lead to the breakdown of ability to care. Evidence suggests that caregivers are ambivalent about expressing their own needs, against a background of lack of information about rights, lack of time and discomfort in confiding in strangers. In addition caregiving may be perceived as a loving or conscious choice, or as an obligation and this can have psychological and physical effects.

A number of factors can help caregivers:

- Commitment to the dying person, and satisfaction with ones caring, can provide greater resilience to stress and burnout
- Professionals can encourage family carers to recognise their own expertise and ability and confirm that they are doing a good job in difficult circumstances
- Trusting relationships, support networks and the sharing of tasks and concerns contribute to security, reassurance, comfort and manageability, and mitigate anxiety, stress, uncertainty and feelings of abandonment

The research on psychosocial and support interventions for carers shows that finding time for attendance at group or one-to-one sessions – or even for telephone support – was problematic for carers. In terms of respite care, carers are reluctant to leave the dying person, so a diversity of types of respite care (in the home and in institutions) should be available.

The focus of carer interventions is repair (when carers cannot cope), reacting to crises, rather than proactively trying to avoid crises when early and timely advice and support could prevent hospital admissions (SCIE 2013).

Psychological support incorporates emotional, social, bereavement and spiritual elements. This should be given to carers throughout the illness trajectory. They need to both prepare for the death and may need support after the death. This can be delivered in groups or individually. Sessions can give carers opportunities to meet and support each other, as well as being used to give carers information about services available to them.

11.5 Acquiring nursing and practical skills

Carers need help with personal, nursing and medical care for the patient (EAPC 2010) and a review showed that practical and information needs of carers included:

- medication and pain management
- physical symptoms and comfort
- nutrition
- personal hygiene and elimination
- professional/local support and emergency measures

Home-based palliative care services have, thus far, focused insufficiently on assisting carers to acquire practical nursing and the practical skills needed to provide care. This review described and critiqued the research literature on interventions which may assist carers to provide physical care to family members suffering, in this case from cancer, but would equally apply to other life limiting conditions. Structured education programmes for lay-carers result in positive patient and lay-carer outcomes relating to symptom management. Providing lay-carers with the knowledge to understand the rationale of good symptom management adds to their confidence in administering the right drug for the right symptom at the right time. This generates improved patient outcomes and decreases unwanted and inappropriate admissions to acute care facilities (Bee, Barnes et al. 2009).

Carers should be trained to carry out basic nursing tasks and to facilitate this; services should be commissioned that address the need for patients to have analgesia at all times, as poor pain relief is often responsible for emergency admissions. Syringe drivers and palliative care kits should be available at all times. The provision of personal alarms for frail patients should be considered as should the use of Telecare (initiatives using this have been discussed above, page (SCIE 2013).

There is resistance from some palliative care service providers about the appropriateness of teaching lay-carers to prepare and administer subcutaneous injections. This has been partly due to a perception that the task is too burdensome for family members, that is, it generates unnecessary stress and anxiety with possible negative consequences in bereavement. In addition, there is organisational and individual uncertainty related to legal, jurisdictional and scope of practice issues for registered nurses and lay-carers. There is some literature confirming the ability of lay-carers to successfully administer pre-prepared syringes for symptom control, but there are few studies concerning the practice of also teaching lay-carers to prepare injections.

However, an educational package that supports lay-carers to safely manage breakthrough subcutaneous injections for home-based palliative care patients has been identified and described previously .The intervention educated and supported lay-carers to competently and safely prepare, store and administer subcutaneous injections; to monitor subcutaneous sites; to manage a medication administration record suitable for easy assessment by health professionals and to understand the uses of common medications used in palliative care.

11.5.1 Audit of the use of 'just-in case' boxes as part of a Local Enhanced Service agreement for EoL care

This project links with the idea of carers being able to administer pain relief to their patients in their own home when they need it (Westwood, Bagshaw et al. 2012).

Abstract (abridged)

Background: The local enhanced service for end of life care was started by Worcestershire Primary Care Trust in 2009, with the aim of developing good practice and improving EOL care. GPs were asked to sign up to and fully adopt the Gold Standards Framework (GSF). Access to palliative care medications and proactive management of symptom control are key components of GSF, and to support this 'just-in case' boxes were launched in April 2010. It was anticipated that the use of the boxes would avoid the distress caused by poor access to medications in out of hours, by anticipating symptom control needs and enabling availability of key medications in the patient's home.

Outcomes: To assess the success of this initiative a 6 month audit was undertaken between May and October 2010.

Results: A total of 66 boxes were placed in patients homes. Fifteen of those boxes were not used. No patients were transferred into the acute trust (one patient was transferred to a care home), meaning that 65 people remained in their own home at time of death, with 48 of those patients' end of life care being supported by provision of anticipatory medication. Only 6% of the responses reported any resistance to use of the boxes, either by the patient or their family. Provision of the boxes improved symptom control in 55% of the cases, and 89% of the boxes were reported as containing the most appropriate drugs. A cost saving of at least £69,140 was made. This was calculated by multiplying the number of times the provision of the just-in case box prevented use of a further healthcare service by the average cost for that specific c episode of care. This can be compared favourably to the cost of providing the drugs, being £3,346.

11.5.2 Development and Evaluation of an Intervention to Assist Lay-Carers to Provide Physical Care to Family Members at the End-of-Life

Given that research has shown that lay-carers would appreciate more practical training and support in providing physical nursing care in the home, this project sought to meet their information, support and practical needs concerning the provision of physical nursing care (i.e. administering medicines, feeding, moving and positioning etc.). The project was conducted in partnership with lay-carers (of cancer patients). However, as stated earlier, needs of carers are often similar whatever the medical condition of the patient. Carers need to be able to control physical symptoms including pain, fatigue weight and appetite loss. Some family members feel incapacitated in a caring role, they find it difficult to know what symptoms to monitor, how to interpret these accurately and when to contact a professional. Studies of end-of-life care report on the poor quality of information provided by health professionals and suggest that family carers need more help with practical and nursing skills. A lack of these can result in an abandonment of a home death and transfer to hospital. However, the presence of District Nurses and GPs could offer some opportunities for passing on caregiving and palliative care skills. There is little research to date on the benefits of physically focussed, well defined and evaluated home care interventions for carers of family members receiving palliative care (Luker, Cooke et al. 2015)

Abstract (abridged)

Purpose: To design and evaluate an intervention to address carers' needs for practical information and support skills when caring for a person with cancer at end of life.

Method:
Phase 1. 29 carers were interviewed about need for practical information, support skills and their preferences for information delivery. The preferred format was a booklet.

Phase 2. Evaluated the booklet. 31 carers and 14 district nurses participated.
Validated questionnaires: on perceptions of caregiving and carer health before and after the booklet was used and interviews with both carers and nurses were undertaken. 24 carers completed both interviews.

Results:
Carers were positive about the booklet, however many carers would have liked the booklet earlier.
Carers reported feeling more positive about caregiving, and more reassured and competent in their role.
District nurses found the booklet useful and reported receiving fewer phone calls from study carers than others in similar situations.

Conclusions: The booklet intervention was a source of reassurance to carers and it has the potential to be incorporated into everyday practice. The challenge is in when and how to distribute the booklet and more work is required on the timing of delivery in order to maximise the usefulness of booklet to carers.

11.6 Information for carers

Carers need both practical and financial information (for example, on welfare benefits, charities, modifications to the home, grants, etc) (EAPC 2010). The Norfolk group have a checklist of things that a carer may need to resolve; funeral arrangements, finance and wills which was co-designed (P.C. TA, 13/4/2015). Providing information within the MHMC programme is likely to require multiple formats to be optimally effective. While many people likely to become involved with the programme will be comfortable in using the internet and online resources it should be recognised that many more will not have consistent access to a computer or confidence in using one. Links to web resources should be clearly given and it must be remembered that printing out materials in homes may not be possible.

We need to understand better how different people make sense of the end of life and how they use information relevant to their circumstances. This includes looking at such factors as age, gender, ethnicity and education level in relation to different communication media (video clips could be available for loan for example) and some web sites contain vignettes or case studies. Well-designed printed materials remain valuable to carers and the use of telephone contacts, either for routine follow up or as part of a targeted educational and support intervention is also viable (for example tele video conferencing for depression). The timeliness of information to address carer needs is also an important focus (King, Brooks et al. 2014). However, carers require information throughout the whole end of life process and beyond National EoL Care Programme (NEoLCP).

11.6.1 ICT, E-based & Tele healthcare initiatives

Initiatives using a combination of the above can result in carers feeling better informed and more ‘empowered’ by the improved access to information made possible by these schemes. Carers involved with them do not worry that these may replace traditional ‘face to face’ service delivery.

11.6.2 Disease specific information

There may be uncertainty about the duration and nature of the patient’s illness and, particularly for conditions other than cancer, it is difficult to predict their illness trajectory. Carers may be in this role for a relatively short time and, therefore, require a rapid response to their needs (EAPC 2010). Carers suggest that expert advice on disease conditions is both necessary but not always available. This is a real problem for generalist and specialist palliative services, and probably best addressed by liaison with specialists (SCIE 2013). Again, the Norfolk initiative (page 31) offers to carers’ advice from Hospice specialists on different conditions. Differences in disease trajectories, awareness of the terminal nature disease and available support translate into different carer experiences (Grande, Stajduhar et al. 2009).Carers need substantial and accessible clinical information, to help them take part, as proxies, in the decision-making process throughout the course of a disease (EAPC 2010).Carers are central partners in care who need to be informed about the patient’s medical condition and how it is likely to develop (SCIE 2013).

11.6.3 Information about the dying process

In terms of the dying process, both patients and families need to know when the dying phase is approaching. There is evidence that this transition is not always explained and described to patients and carers. Because they spend a lot to time with patients and carers, district nurses are ideally placed to recognise and discuss this with families and carers. Although they find this a challenge, it is essential preparation for a good death for all concerned. People's responses to the prognosis including patients, includes unawareness, denial and anger. Thus a conversation about this has to be timely and consider all those involved in caring. A recent study examined the process of breaking such news to patients and their families by district nurses. This suggests that they could be better trained and prepared for this task (Griffiths, Ewing et al. 2015).

Abstract (abridged)

Background: UK District Nurses have an important role in enabling a good death. Patients and families need to know the patient is approaching the dying phase, yet evidence suggests breaking bad news about the patient's transition to dying rarely happens. District Nurses are with families during the dying phase and are ideally placed to recognise and discuss the transition to dying.

Aim: To explore the role of District Nurses in breaking bad news of transition to dying.

Design: Qualitative focus groups.

Setting: Primary care (District Nurse service); Four National Health Service Trusts, North West England.

Participants: A total of 40 District Nurses across the Trusts, all Registered General Nurse qualified.
Median number of years as a District Nurse was 12.5. All had palliative cancer patients on their caseloads.

Results: District Nurses' role in breaking bad news of transition to dying was challenging, but the conversation was described as essential preparation for a good death. Four main challenges with the conversations were patients' responses to the prognosis (unawareness, denial and anger), timing the conversation, complexities of the home environment and limited preparation in this aspect of their work.

Conclusions: District Nurses are with patients during their last weeks of life. While other colleagues can avoid breaking bad news of transition to dying, District Nurses have no choice if they are to provide optimal end of life care. While ideally placed to carry out this work,

11.7 HCP input

In addition to the discussions above about HCP input to end of life training and education and their own need for specialist training, considering that Palliative care emphasizes an interdisciplinary approach to care to improve quality of life and relieve symptoms and that much of this is provided in the community, it seems odd that the use of the Community Pharmacists is not more apparent. Pharmacists' are one of the most accessible professionals in the community and their expertise in the therapeutic use of medications is highly regarded. Many palliative care patients have complex medication regimens, involving off-label or off-license prescribing that increases their risk for drug-related problems which they could help with. This non-involvement of community pharmacists may be due to a general lack of understanding of skills and knowledge that particular health professionals could bring to interdisciplinary teams, a lack of rigorous research supporting the necessity for the community pharmacist's involvement in the team, or it could be due to professional tensions. If these barriers can be overcome, community pharmacists are well positioned to become active members of the community palliative care interdisciplinary team and respond to the palliative care needs of patients and their carers, with whom they often have a primary relationship (O'Connor, Pugh et al. 2011).

11.8 The role of Palliative Care Doulas, EoL mentors/facilitators and volunteer mentors

There is some evidence that volunteer mentors, end of life mentors/facilitators and palliative care doulas can be helpful to carers. There is evidence that trained volunteers can help carers cope with EoL care and the Social Action Projects above (page75) are examples of harnessing volunteer help to people in need. Volunteers and/or neighbours can be invaluable in helping a person who is dying to continue doing what they want to do, and take on activities such as dog walking for example, so that patients can keep pets (SCIE 2013). Or volunteers can sit with patients while a carer attends training (Hudson 2009) or simply has time out.

The government have funded 360 EoL care facilitators as part of the EoL care strategy https://www.gov.uk/ government/ publications/end-of-life-care-strategy-fourth-annual-report. The End of Life Care Strategy 2012. UK government report.

Volunteers contribute significantly to palliative patient care. The volunteer may act as a mediator between the patient and the staff. However, we also found some contradictions. Volunteers may take on temporary surrogate family-type relationship roles. They may also take on some of the characteristics of a paid professional. Their role is seen by volunteers as flexible, informal and sometimes peripheral - characteristics some volunteers find stressful (Burbeck, Candy et al. 2014). Beginning with Palliative Care Doulas the roles above will be considered.

11.8.1 Palliative Care Doulas or end of life care facilitators

An Innovative Advanced Practice Nursing Model, the Palliative Care Doula supports patients and their carers. A small retrospective survey measured the effectiveness of this model with patients and carers with life limiting and progressively deteriorating illness. It set out to define what a palliative care doula is and identify positive outcomes.

A palliative care doula (PCD) is an innovative advanced practice model that provides detailed explanation of pathophysiologic changes associated with the disease process to patient and family members at various appropriate points along the continuum to ease the difficulty experienced in decision making. In this survey, the PCD followed three end-stage cancer patients for 1-9 months (average: 5 months). Weekly visits were held with the patient and family throughout the remaining period of the patient’s life. Periodic telephone calls and medical visits were made to keep the PCD informed regarding disease progression to anticipate foreseeable complications and remain proactive in discussing associated risks and burdens. With each visit, the PCD reviewed and clarified the explanations of medical information and encouraged open dialogue regarding future decisions. The study found that the PCD model was found to have the potential to improve patient/family understanding of disease progression through guided advocacy and improve confidence in decision making while increasing emotional support for all involved. It is suggested that future research is needed to explore the efficacy of this model on a larger scale (Lenz, 2011).

11.9 Volunteer mentors: developing training for supporters of lay-carers involved with home based EoL care: A participatory approach

This programme is being piloted (Hardy, Caswell et al. 2014)

Abstract (abridged)

Introduction: Current policy aims to enable more people to die in the place of their choice, and increase the number of people who die at home. Essential to this aspiration is the involvement of lay-carers, usually family or friends of the ill person. The importance of this role is acknowledged at a national level, however carers continue to report many unmet emotional and practical support needs. Innovative approaches are required if we are to improve the experiences of lay-carers in end-of-life situations. In this poster, we report on the progress of an innovative participatory research project, which is developing training for people who support carers. We hope to engage delegates in discussion about the utility of the training for their own organisations and communities.

Aim(s) and method(s): The project aims to develop and pilot an introductory training programme for supporters of carers in end-of-life situations, such as support workers and volunteer mentors. Participatory action research methods have been used to engage with stakeholders including carers and carer support organisations. The programme is being piloted from January 2014.

Results: Currently evaluation activities show the developing programme to be acceptable to a range of stakeholders. Ongoing piloting and evaluation will further test the utility of the programme.

Conclusion: The training programme will be publically available at the end of the project, and free to use. Participatory research methods are a useful way to engage with a range of stakeholders and to raise awareness of end-of-life care issues.

11.10 Methods of delivering education

As in the paediatric diabetes EBS, it is recommended that HCPs who deliver any of the proposed MHMC education programmes are suitably trained in each component and/or have teaching and facilitation skills. As we have seen above, there are various ways to deliver education and training, group, one to one and on line. The method of delivery is affected by many variables, not least that many carers do not wish to leave their dying patients and, therefore, require face to face support and education at home.

11.10.1 One to one

The education programme will require some modules that can be accessed either on line or via one to one contact with carers.

11.10.2 Group sessions

The advantages of group interventions are that they allow for social comparison (the comparison of one's situation with a peer group who are experiencing similar circumstances), social support, sharing of experiences and often require fewer resources.

Comments from carers who had attended group sessions say they can support and facilitate carers to:

- become more aware of services available/information about services
- realise they are not alone, support and help is available and other people care
- be more prepared with knowledge of what lies ahead to be aware of the signs of death in a protected group environment
- gather information about symptoms/medications/speak with doctor
- reap the beneftis of meeting others in the same/similar situations
- be reassured and confident that they are doing a good job
- be supported emotionally, positively and have their needs addressed at a practical level and be more enlightened as to the caring role
- enter into discussions, ask questions, solve problems and share feelings
- accept death and cope with grief
- have an increased understanding of the patient perspective/communication with patient
- see the importance of making time for self-care

11.10.3 Online discussion forums

Online discussion forums are a very successful way of supporting carers. These services, which can be put in place at comparatively low cost, establish a 'virtual' community of likeminded others engaged in similar care-based issues and able to offer each other support, and (potentially) sharing solutions to common problems. Carers UK's Online discussion forum for example, has become the UK's most popular online discussion group specifically aimed at carers. Since 2005, Carers UK has helped carers by providing an online forum which puts them in contact with each other, offering peer to peer support, information and a listening ear and has grown remarkably since its inception. However, health providers need to consider carefully issues of monitoring, ensuring the privacy/anonymity of users and for signposting users to other available support (Yeandle and Fry 2010).

11.10.4 BAME issues

Patients from minority ethnic and/or religious groups experience lower rates of referrals to EoL care services, higher levels of dissatisfaction with services, and perceive some services as culturally inappropriate to them (Evans, Menaca et al. 2012). Additional challenges when dealing with EoL issues with this group include different values and expectations (such as the best place to die, gender and care, and the role of family in care and decisions), attitudes to death, responsibility, and medical treatment, not to mention complications arising from language barriers. These are exacerbated by the low numbers of ethnic minority care workers and nurses.

A more in depth understanding of factors that influence attitudes, beliefs, and behaviours toward EoL issues Is needed, and how these affect decision of BAME communities (these may not be consistent with those of traditional, western-based medicine and family structures and functioning may not fit the conventional paradigm for providing care). Family support has been a consistent theme in end-of-life care research focused on ethnic minorities. African Americans for example, tend to look to family members first in terms of making EoL decisions rather than consulting with medical staff. Hispanic and African Americans prefer the family to voice their wishes than completing written directive and may let them make their end of life decisions (Bullock 2011). More research is needed into the concerns and life worlds of carers from ethnic minorities including their specific communication needs, the differences in social dynamics and traditional values and how grief is experienced and expressed by them (Grande, Stajduhar et al. 2009). Testing programmes and other supportive interventions with minority groups should be undertaken (Hudson, Thomas et al. 2009).

The implementation and evaluation of the Social Action Project in which St Joseph's Hospice will work with specific Black, Asian and Minority Ethnic (BAME) communities to develop social networks in Turkish/Kurdish and Afro Caribbean communities in Hackney, Newham, and the Bengali community in Tower Hamlets and will make an important contribution to the evidence base for the impact of social action in BAME research.

The MHMC project team have succeeded in engaging with the large Jewish population in Prestwich, this is to be applauded and it is suggested that this approach may work with other cultures and groups. However, HCPs engaged in this need to be conversant with the specific knowledge, cultural beliefs, values, and communication patterns used by BAME groups targeted in order to introduce them to, and help them engage with, end-of-life care services and education. Behaviours which are culturally bound including communication patterns, values and beliefs and interpretations affect how information given to them by members of a care team is perceived and understood, and their expectations of care may conflict with those of the HCPs offering this care (Bullock 2011).

As described above this website has several BAME initiatives across the UK

http://www.familycarers.org.uk/resources/by-tag/black-minority-ethnic-carers

11.10.4 LGBT issues

This is a group with their own specific needs which are important to address rather than a “one fits all” approach. There is a growing literature and evidence base around this group and most of this is described in this EBS.

11.10.5 Post bereavement

The National End of Life Care Programme (NEoLCP) End of Life Care Pathway advocates seeing carers through this stage. Bereavement groups are popular therapy for bereaved carers. Group therapy in this form includes common therapeutic factors such as sharing and support, interpersonal learning, and meaning-making and can affect both group functioning and individual outcomes (Rice 2015). It may be that the MHMC programme could consider an intervention of this type facilitated by an appropriate HCP.

11.10.6 Logistical considerations

Some points to note when planning carer training courses:

- Governance systems should be transparent, with unambiguous targets, outputs and outcomes specified in contractual documentation
- Programmes should be flexible in terms of local delivery and responsiveness to specific carer needs
- Output-related funding models should be considered
- Effective Management Information systems should be put in place
- Innovative marketing and recruitment techniques are needed
- Milestones, targets and costs need to be ambitious but achievable
- Innovative ways of supporting carers are needed, drawing on partnerships with independent sector providers and those who support, engage with or employ carers

Practical issues to consider should include:

- identifying suitable venues
- establishing workable delivery arrangements
- developing strategies for recruitment and referral pathways
- identifying the most appropriate ways to offer alternative care support

Curriculum

Delivering successful training involves:

- Tailoring the training programme to meet the needs of carers living in the locality

- Exploring fully all challenges of delivering to different groups of carers [28]
- Mapping and assessing carers' needs
- Existing forms of support /training (covered in this scan)
- Assess fully the achievability of milestones, targets and costs prior to implementation

Demonstrating that supporting carers in this manner can have a long-term positive impact on their health and well-being will help funding applications.

- Consider staffing requirements, costs, (including their training and accreditation). For example, project manager, a project co-ordinator, and module facilitators
- Consider costs of delivering sessions
- Consider initial set-up costs (monitoring access, recruitment, course materials, delivery methods, practical considerations (refreshments, travel reimbursement [29], reminder systems for carers)
- Decide whether the course is free or incurs a cost to carers
- Ensure the ongoing delivery costs are financially viable and that these can be met for the duration of the programme.
- Try to structure the course to agencies that might want to buy a number of training places for carers

NB. Administration/promotional activities always cost more than envisaged!

Funding could be secured to facilitate:

- a longer term mutual support group
- a counselling service
- a helpline
- pathway for carers into other services
- the development of an on-line support forum for its specialist target group of carers

11.10.7 Monitoring access

This gathers knowledge about local carers' needs and circumstances. It can also help gauge who is not accessing the service. All relevant details about the carers should be recorded in a brief format in a one to one meeting, the moment the carer enters the service, including: age, gender, ethnicity, employment status, and who the carer is caring for / their condition.

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[28] *Ideally using Census of Population data (to establish carer prevalence in the area), supplemented with intelligence from other data sources such as from groups involved in supporting carers in the locality.*

[29] *Carers are more likely to attend training sessions if travel and alternative care costs are covered. The provision of a meal also helps.*

11.10.8 Recruitment

Training programmes for carers need to reach ‘hidden carers’ as well as those already engaging with services. The CwC programme mainly recruited spouses caring for people with long term conditions recruited mainly from carers’ organisations. These were the people most likely to attend courses whereas LGBT carers and carers of people from BAME groups would only attend one module. Those caring for people with complex conditions, dementia and those near the end of life were less likely to benefit in terms of certain aspects of health and well-being and may benefit from additional support.

Promotional literature: information sheets, maps, contact telephone numbers for carers to seek advice. Highlight in promotional material the benefits for carers (a break from their busy and often stressful lives) and for those being cared for (a more informed carer).

Word of mouth: promotional material distributed by carers’ centres and other voluntary organisations involved in supporting carers

Work with other local organisations: voluntary groups, local authorities and employers.

Vigorous outreach work: in order to access carers from ‘harder to reach’ communities/hidden carers (underway by MHMC team).

Avoid advertising to family carers only. This may exclude LGBT and other minority groups (Scottish 2010)

Use of GP and NHS referrals: Request existing members of staff become a ‘carers’ champion’ (e.g. a receptionist). This can be an effective way of achieving referrals.

Course materials:

These should be developed by experts in the field (for example, by Health Psychologists) and encourage carers to explore their own situations and concerns. CwC have some materials for general use. Materials can also be bespoke to local carers needs.

There is a facilitator training programme developed for CwC which can be accessed on-line. Training facilitators can give them confidence to deal emotional and other issues that can arise when working with carers. If this is not possible, effective facilitators should have:

- Previous experience of delivering teaching/training
- A sympathetic, empathic approach, possibly personal experience of caring
- Sensitivity to different BAME, LGBT groups

Flexibility

- The course should be both structured and flexible
- Where different sessions deal with a range of caring issues, a ‘pick n choose’ approach may be suitable
- Allow carers to attend according to individual needs
- Facilitators can invite explorations of individual concerns with others and/or individually
- Delivering the course material and lead/facilitate the group allowing experienced carers to support others
- A tailored module specifically geared to carers in the locality, including targeted information about locally available services and support is useful

Practical considerations

- Assess the practicalities of provision
- Ensure that the needs of target groups are considered prior to offering the programme
- It is essential to tailor modules to specific carers’ needs
- Maximise uptake by a sensible and practical schedule. That is, mornings, afternoons, evenings, weekends or even lunch-time sessions. Reduced the length of each session from three to two-and-a-half hours if necessary
- Be flexible about high group numbers, small groups are intimate and ‘workable’

Identifying appealing venues

- Comfortable and welcoming reception. Refreshments upon arrival and a meal were much appreciated by carers
- Balance nice venue in an attractive location for accessibility, by public transport for e.g. some carers have difficulties in making complex travel arrangements
- Ensure there is a budget to cover travelling costs incurred by carers to be reimbursed immediately and without fuss
- Ideally have access to a number of different venues in the locality which can be used to cater for specific carers’ needs
- Free car parking nearby is desirable or with parking costs refundable
- Evening courses a venue in a safe, well-lit location is essential

Alternative care support

- A budget enabling provider to refund any costs carers incurred arranging alternative care. This can be crucial in some cases offering opportunities to all levels of carers. Nearly 30% of carers said they had needed to arrange alternative support in order to attend

- This should be provided by 'trusted and experienced' voluntary sector groups [30]
- Ensure that carers know about the service offered in good time
- Carers and those cared for have good reasons for not accessing this service. These could be addressed with care
- When courses are established uptake increases

11.10.9 Future planning

Importance of carefully managing programme delivery costs. Cost issues can arise when modules run below planned capacity. Some providers achieved a 'cost per carer place' (for a single module delivered in face-to-face sessions attended by 8-11 carers) of less than £125, including management, administrative and monitoring costs. Consider from the outset long-term plans for a carer training programme. If the budget can cover the cost of alternative care, organisations should include it in their plans for providing training for carers.

A rigorous evaluation of the programme's development, including its impact on carers' lives, is recommended as a good way of demonstrating the course's value and the difference it can make not just to carers but to the wider health and social care system[31].

Other issues to address are

- Explore strategies for enhancing uptake and obtaining enough participants to make programmes viable
- Outline specific barriers to attending programmes and then investigate strategies to address them
- Consider the option for one-on-one interventions to delivered at home
- Time is a main obstacle to attending programmes. Shorter versions of programme could be offered
- A multimedia version of the programme could be developed for carers to watch at a convenient time
- The programme may need to consider a variety of times or locations to maximise carer attendance

The next section shows the proposed MHMC programme mapped against current, existing, local, regional and national educational, evidence based (co-designed where possible) programmers and initiatives. Where there are gaps in the curriculum which would need to be filled in order to meet guidelines, curricula, recommendations, these are highlighted with recommendations for fulfilling these.

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[30] *Staff involved in delivering CwC reported that offering alternative care was essential.*

[31] *Points extracted from "Delivering Training to Carers. A practical guide based on findings from the National Evaluation of the Caring with Confidence programmeme" CIRCLE. (Centre for International Research on Care, Labour and Equalities). University of Leeds. December 2011*

Section 12. Mapping exercise

As in previous phases, the mapping exercise (table 9) exemplifies what a robust educational programme for carers of those at EoL would look like.

Table 8. MHMC proposed programme

MHMC topics	Issues to address
Educational needs	Clarify gold standards Advance Care Planning (ACP) Washing and dressing Skin & wound care Safe lifting techniques Administering medicines/injecting Diet
Psychological needs	Carers' knowledge, skills, understanding of the role
Preparation for caring	Explore needs of carers
Practical needs	Local services available/to be developed Financial benefits Communication with healthcare professionals
Service Development	Explore provision for BAME and LGBT carers Explore an evaluation tool

Table 19. Mapping exercise

NHS NICE/other guidelines	**MHNC Modules** **SUGGESTED ACTIVITY**	**Programme, resources available**
Guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients. Guidelines, 1, 2 & 3 (Page 108 of this scan) (Hudson, Remedios et al. 2012) **Macmillan Cancer Support, NHS Camden and NHS Islington** “A quick guide to identifying patients for supportive and palliative care”	**GAP** **IDENTIFYING CARERS**	GP practices to identify patients approaching the end of their life and, potentially, approach family carers with PENNINE CARE NHS FOUNDATION TRUST information https://www.gov.uk/government/publications/end-of-life-care-strategy-fourth-annual-report Supporting those with caring responsibilities to identify themselves as carers at an early stage https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213804/dh_122393.pdf Centre for Palliative Care
GAPS **CARE OF CARERS: PREPARING CARERS FOR CARING**		
NICE quality-statement-2- communication-and-information Information about treatment and care options, medication and what to expect at each stage of the journey towards the end of life http://www.nice.org.uk/guidance/qs13/chapter/quality-statement-2-	**(MODULE 1)** **FAMILY MEETINGS** **GENERAL ISSUES**	**Caring with Confidence** http://www.carersuk.org/help-and-advice **Dying matters** Planning ahead Understanding death and dying Advance care planning for volunteers Being with someone when they die

communication-and-information **Family meetings in palliative care: Multidisciplinary practice guidelines** see page 101 http:/centreforpallcare.org/assets/uploads/Family_Meetings_in_PC_Multidisciplinary_Clinical_Practice_Guidelines.pfdDying matters **Guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients.** Assessing Need and Establishing a Plan of Care (Guidelines 4 to 10). Page 145 of this scan. (Hudson, P., C. Remedios, et al. 2012). .		Talking about death and dying Information for carers Concerns about end of life care Legal and Ethical Issues http://dyingmatters.org/gp_page/supporting-carers-cope **Choices End of life issues** Care and support for carers Accessing palliative care **HEALTHTALK.org** http://www.healthtalk.org/peoples-experiences/dying-bereavement/caring-someone-terminal-illness/topics **Hospice UK** Information resources on disease process, trajectory and prognosis Information about the dying process and symptom management in a timely way http://www.hospiceuk.org/what-we-offer/care-support-programmes/family-and-carers **MACMILLAN.** Hello, and how are You? A GUIDE FOR CARERS BY CARERS http://be.Macmillan.org.uk/Downloads/MAC5767HelloAndHowAreYou.

		pdf **Marie Curie Film guides** Preparing for the end of life **NHS Choices** www.nhs.uk/Planners/end-of-life-care/Pages/what-it-involves-and-when-it-starts.aspx
(EAPC 2010) Benefits and financial support is a need for carers of dying patients	**(MODULE 2)** **ACCESSING FINANCIAL SUPPORT AND BENEFITS** **DWP** **Grants** **Taxi cards** **Blue badges.**	**Carers UK** http://www.carersuk.org/help-and-advice DOWNLOADS available on; Attendance allowance Bedroom tax Benefit cap Bereavement Care act FAQ Care standards FAQ Carers allowance Carers assessment **Caring with Confidence** **CLAHRC** Greater Manchester ongoing research study; “Uncovering the contribution, costs and economic value of family caregiving”

		http://clahrc-gm.nihr.ac.uk/our-work/community-services/dimbleby-project/ **Hospice UK** Access to welfare or benefits advice. http://www.hospiceuk.org/what-we-offer/care-support-programmes/family-and-carers **Marie Curie Cancer Care** Offer advice on money matters, including the blue badge scheme, Attendance Allowance and Disability Living Allowance, Carer's Credit, Carer's Allowance, Income Support, Housing Benefit and Council Tax **Carers direct** http://www.nhs.uk/CarersDirect/moneyandlegal/Pages/Moneyandlegalhome.aspx
"Carers should be supported to stay mentally and physically well and treated with dignity" (Hudson, Remedios et al. 2012) Guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients	**(MODULE 3)** **CARER ASSESSMENT** **PHYSICAL AND PSYCHOLOGICAL** **Psychological support** **Emotional** **Social**	**Caring with Confidence** Clinical practice guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213804/dh_122393.pdfCentre for Palliative Care **Beyond Blue** Reduce Stress handout Sleep well handout

	Bereavement **Spiritual**	http://www.beyondblue.org.au/ Oxford University and Sobell Hospice Charity pilot project For physical and personal care skills (page **Error! Bookmark not defined.**)
	(MODULE 4) **ADVANCED CARE PLANNING &** **ADVANCED DIRECTIVES**	**Caring with Confidence** **Dying matters** Advance care planning for volunteers
NICE quality-statement-2-communication-and-information Information about treatment and care options, medication and what to expect at each stage of the journey towards the end of life http://www.nice.org.uk/guidance/qs13/chapter/quality-statement-2-communication-and-information Guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients Part 3: Preparing for Death Guidelines 11-14	**GAPS** **PREPARING FOR CARING (MODULE 5)** **Preparation for specific disease trajectories and effects**	**Dying matters** Understanding death and dying Choices End of life issues Progression of a terminal illness http://dyingmatters.org/gp_page/supporting-carers-cope **Hospice UK** Information resources on disease process, trajectory and prognosis. Information about the dying process and symptom management in a timely way. **Macmillan** http://www.hospiceuk.org/what-we-offer/care-support-prwww.Macmillan.org.uk/Cancerinformation/Endoflife/Endoflife.aspxog

		rammes/family-and-carers **Marie Curie** www.mariecurie.org.uk/Documents/PATIENTS-CARERS-FAMILIES/publications-and-guides/end-of-life-guide.pdf
CARE OF PATIENTS		
	MEDICAL ISSUES	An educational package to support lay-carers to manage breakthrough subcutaneous injections
	MENTAL HEALTH ISSUES Managing psychological symptoms low mood stress anxiety cognitive and neurological impairment agitation distress aggression	**CARING WITH CONFIDENCE** **Macmillan** Hello and how are You? A guide for carers by carers Sections for carers and patients on; Depression Anxiety Anger Frustration Fear
	PERSONAL CARE	**Hospice UK** Recommends for carers, ‘information, training or

	Skin care Hydration Nutrition	education' on how to provide specific care tasks, http://www.hospiceuk.org/what-we-offer/care-support-programmes/family-and-carers **Macmillan** Hello and how are You? A guide for carers by carers Section on personal care **Marie Curie Cancer Care** Offer help and support for carers including respite, help with household tasks and personal care Marie Curie – film guides Helping a person to wash Helping with mouth care Making a person comfortable in bed Rolling a person in bed Healthy eating Helping a person take medication Supporting a person to stand and walk Helping a person to relax www.mariecurie.org.uk/patientsandcarers
Local Authority Support for Carers	**GAPS**	**St John's Ambulance**

OT assessment for moving and handling. Free specialist equipment may be available. Assessing needs and determining eligibility (PDF) **NHS. MOVING AND HANDLING THE PERSON YOU CARE FOR** http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/mobility-problems-carers.aspx	**FIRST AID** **SAFE LIFTING/MOVING TECHNIQUES FOR CARERS**	First aid courses for the public http://www.sja.org.uk/sja/training-courses/courses-for-the-general-public.aspx **Caring with Confidence** Domiciliary occupational therapy service which supplies equipment and adaptations. **Hospice at home Service** (EAPC 2010) **Hospice UK** http://www.hospiceuk.org/what-we-offer/care-support-programmes/family-and-carers Recommends for carers, 'information, training or education' in strategies for safe moving and handling of the patient **Macmillan**: Hello and how are You? A guide for carers by carers. Sections on: Moving and handling Organising equipment and transport **Marie Curie Cancer Care** Film guides

		Rolling a person in bed Supporting a person to stand and walk Offer help and support for carers including help with household tasks and personal care mariecurie.org.uk/patientsandcarers **Princess Royal Trust for Carers** (PRTC). Moving and handling 2015 in Scotland http://www.prtlcc.org.uk/en-us/courses/courses-movinghandling.aspx Moving and handling at home - a carers' guide to what not to do **York Carers Centre** https://www.youtube.com/watch?v=dHxzxXoEeyM
CLAHRC GM Greater Manchester incorporates a Wound Care programme which is on-going with a focus on priority setting involving: patients/carers/nurses/ pharmacists	MANAGING PHYSICAL SYMPTOMS Wound care	The MHMC project team have received non clinical feedback on the presentation on wound care. Some technical elements of the presentation could be simplified. Often wounds are symptoms of underlying conditions with limited evidence that dressings will contribute to healing. Wider issues therefore, could be addressed in this unit such as reinforcing important messages that underpin the

		management of wounds including: The importance of pressure relief in pressure ulcer management and off-loading for foot ulcer management.
Centre for palliative Care. Australia EOLRSF; Noisy breathing at end of life (2013) EMRPCC: End of life care: Management of respiratory secretions (2013)	**Breathlessness**	**Hospice UK** Information resources on disease process, trajectory and prognosis. Information about the dying process and symptom management in a timely way. http://www.hospiceuk.org/what-we-offer/care-support-programmes/family-and-carers
Centre for Palliative Care. Australia EMRPCC: End of life care: Management of respiratory secretions (2013) EMRPCC: Opioid conversion ratios - Guide to practice 2013 v. 2 (Nov 2014) MRPCC: Syringe driver drug compatibilities - Practice guidelines 2013 v. 2 (Nov 2014) Palliative care nurse practitioner - Symptom assessment guide (2011)	**Swallowing difficulties** **Pain** **Incontinence**	**Hospice UK** Information resources on disease process, trajectory and prognosis. Information about the dying process and symptom management in a timely way. http://www.hospiceuk.org/what-we-offer/care-support-programmes/family-and-carers **NHS choices**. Managing pain and other symptoms. Deals with other symptoms such as nausea, vomiting, loss of appetite and constipation www.nhs.uk/Planners/end-of-life-care/Pages/controlling-

		pain-and-other-symptoms.aspx
Centre for palliative Care. Australia EMRPCC: Opioid conversion ratios - Guide to practice 2013 v. 2 (Nov 2014) MRPCC: Syringe driver drug compatibilities - Practice guidelines 2013 v. 2 (Nov 2014) Palliative care nurse practitioner - Symptom assessment guide (2011)	Managing complications and risk assessment **GAPS** **MEDICINES MANAGEMENT** **INJECTION TECHNIQUES**	**Community pharmacy involvement** **Carer one to one education programme. An educational package to support lay-carers to manage breakthrough subcutaneous injections (See section 4)** **Hospice UK** Information resources on disease process, trajectory and prognosis. Information about the dying process and symptom management in a timely way. http://www.hospiceuk.org/what-we-offer/care-support-programmes/family-and-carers
	GAP **LESBIAN, GAY, BISEXUAL AND TRANSEXUAL**	**Age UK** Offers support for older Lesbian, Gay, Bisexual and Transgender people **DYING MATTERS** Meaning, faith & belief **NHS** Route to Success: Achieving Quality for Lesbian, Gay, Bisexual and Transgender People.

		This National End of Life Care Programme guide
	GAP **BLACK AND MINORITY ETHNIC GROUPS**	**The Afiya Trust webpage** http://www.afiya-trust.org **National Black Carers and Carers Workers Network** (NBCCWN) http://www.scie-socialcareonline.org.uk/beyond-we-care-too-putting-black-carers-in-the-picture/r/a11G000000182U6IAI **ANSWAAR** **LEICESTER** Support network www.ansaar.org **CHECK OUT FOR MORE INITIATIVES** http://www.familycarers.org.uk/resources/by-tag/black-minority-ethnic-carers **CARING With CONFIDENCE** **DYING MATTERS** Meaning, Faith and Belief **CARERS SCOTLAND** A programme for black and minority ethnic (BAME) carers

		and carers in rural communities
	GAP **TRAINING of DOULAS, END OF LIFE CARE FACILTATORS AND VOLUNTEERS**	**GOOD PRACTICE MODELS & SOCIAL ACTION PROJECTS**
Guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients. 15-19 (Hudson, Remedios et al. 2012) **UK Government** Guide to legal obligations in the event of a death, plus issues such as the involvement of the coroner and arranging the funeral. www.gov.uk/after-a-death/overview	**GAP** **RE-ABLEMENT: COPING AFTER CARING**	**Caring With Confidence** **Choices** End of life issues Moving on as a carer Bereavement support Registering a death Arranging a funeral **Dying matters** What to do after someone dies Coping with bereavement Telling others about a death http://dyingmatters.org/gp_page/supporting-carers-cope **MARIE CURIE** Adjusting to life after caring Ensure that the carer sees their General practitioner

		http://www.patient.co.uk/doctor/end-of-life-care-pro Employment and work (returning to work) **NCPC** Six steps to improve support in bereavement http://dyingmatters.org/sites/default/files/Life%20After%20Death%20FINAL(1).pdf
Guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients. Guideline 20 (Hudson, Remedios et al. 2012)	**GAP** **EVALUATION**	Following the death of a patient, the interdisciplinary team should discuss with family caregiver(s) the quality of care provided to the patient and the nature of the death. All relevant discussions, assessments, and outcomes should be clearly documented in the most appropriate location (as per the service protocol). A clear process for complaints and feedback with regard to the quality of health professional support should be easily accessible to patients and family caregivers (Hudson, Trauer et al. 2012).

Section 13. Conclusions

Preparing caregivers will be a major issue to address in the education programme. It is considered that there a significant gaps in the MHMC proposed programme. A number of ‘good practice models’ across the UK and beyond are presented. Existing written and web based resources are described. EoL guidelines, pathways and mandatory support for carers have been outlined and, as in paediatric diabetes, the issue of training HCPs in end of life issues is and in delivering these is flagged. Finally, recommendations for training, supporting and educating carers have been suggested and the mapping exercise constitutes a plan for the design of a complete educational programme. Some courses specific to those envisaged by the MHMC project have been identified and described. Solutions have been offered for filling gaps in the proposed programme so that a completed programme would fulfil all appropriate guidelines.

In terms of delivering a programme, one size does not fit all and carers will require different formats depending on their situation and individual preferences. This can include written material, face to face interaction - one to one or in groups - and there is good potential for web based programmes. Some family caregivers will need more comprehensive, focused interventions based on thorough assessments of their situation and resources.

It is recommended that the MHMC team contact CLAHRC Greater Manchester because they have an End-of-Life programme which includes the following projects and which are relevant to PENNINE CARE NHS FOUNDATION TRUSTs proposed programme.

1. “Uncovering the contribution, costs and economic value of family caregiving”

http://clahrc-gm.nihr.ac.uk/our-work/community-services/dimbleby-project/

2. “Mapping pathways of care for end-of-life. A mapping exercise to assess the provision of end-of-life care across Manchester will explore performance in relation to the facilitation of Death in Usual Place of Residence (DiUPR)”. This will begin with a quantitative investigation of performance across Manchester, followed by a qualitative investigation of the underlying factors affecting performance, in order to develop a range of critical success factors in the delivery of high quality choice-led end-of-life care. http://clahrc-gm.nihr.ac.uk/our-work/community-services/end-of-life-pathways-of-care/

It is also suggested that MHMC project undertake a quality report on Pennine Care NHS Foundation Trusts present EoL care. Lincolnshire Community Health Services NHS Trust's inspection is one such example. This was undertaken in September 2014 with the final report being published in December 2014. People who had looked after others at the end-of-life were involved with the report and influenced its findings.

This report was based around five questions which encompass most issues in EoL care:

- Is it safe?
- Is is effective?
- Is it caring?
- Is it responsive to people's needs?
- Is it well-led?

The report is available through the following link:

http://www.cqc.org.uk/sites/default/files/ry5_coreservice_end_of_life_care_lincolnshire_community_health_services_nhs_trust_scheduled_20140905.pdf

13. 1 Future evaluation and the current state of EoL science

There are a lack of assessment tools for carers' needs and theoretical models to underpin these. However, interventions need to be evaluated in terms of their efficacy, effectiveness and cost-effectiveness .Evaluations of interventions rarely assess specific outcomes for carers and the well-documented challenges of undertaking end of life/palliative care research contributes to this. There is limited research in the UK and also little information in this field about carers of non-cancer patients (EAPC 2010). In terms of evaluating any MHMC course that is designed, the current state of the science related to palliative/EoL remains, to date, at a descriptive level. Thus there is little scientific evidence as yet on which to base practice related to caregivers in palliative and end-of-life care. Although descriptive research is important, research studies need to progress to being prospective, longitudinal, and trajectory based in order to elucidate the challenges faced by caregivers. Studies should also be conceptually and methodologically rigorous with theory driven research questions. Only then will an evidence base be constructed which will eventually improve practice.

Measurement strategies and tools, relevant, feasible, and high-priority outcome variables related to caregiver-reported outcome measures still require development, refinement and testing which will then result in an expanded collection of valid, reliable, and clinically useful options to measure outcome and other variables in end of life intervention research. Sophisticated and creative statistical methods will enable researchers to explore the nuances of relationships among variables, influencing factors, and inter-individual differences resulting in a scientific evidence base in palliative and end-of-life research (McGuire, Grant et al. 2012).

In order for the UoM to assist with ideas for evaluation, MHMC should consider what it requires from its proposed programme in terms of measuring the effects, (or outcome(s)), of their intervention (education and training for carers). Deciding what the most important outcome would be the first step to choosing measures for this evaluation. In terms of preparedness for example, it would be useful to know if preparedness and competence were correlated. The transactional model of stress and coping also appears to be useful in this regard because the Australian work has indicated that positive aspects of the caregiver role were bolstered by one intervention, and preparedness improved in several interventions and negative reactions to the family caregiver experience buffered when caregivers are better prepared for their role (Hudson and Aranda 2013).

General carer related measures which could be considered in an evaluation:

- Functional status: physical and social functioning, Role limitations attributable to physical/emotional problems
- Wellbeing: Mental health: energy and fatigue; pain
- Overall evaluation of health and those that measure generic quality of life

Other measures include questionnaires which measure:

- General Health
- Caregiver Competence
- Preparedness for Caregiving
- Rewards for caregiving

The psychometric properties of all of these instruments have been tested previously with family caregiver palliative care populations (Parker, Arksey et al. 2010). Some programmes have evaluated carer's reactions and appendix 2 contains the questionnaire for The "Hospital-based Group Education Programme for Carers*"* (Hudson and Aranda 2013).

Organisational measures include the **(ELCQuA) The End of Life Care Quality Assessment tool**, an online tool to monitor and compare end-of-life care services with similar organisations locally and nationally. Progress can be assessed against a set of core specifications based on the Department of Health's quality markers and measures for end-of-life care.

www.elcqua.org.uk

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Appendices

Appendix 1 VF appraisal of the Caring with Confidence programme

The *Caring with Confidence* (CwC) programme aimed to provide support to 37,000 carers in England. It was the largest programme of training for carers ever planned in the UK, with a total budget of £15.2m over three years. It was designed to provide training and support to carers, aimed at providing them with more choice and control in different aspects of their lives. However, rather than teaching clinical caring skills to carers, courses were about carer support and strategies to improve their health and well-being.

- **It's about acknowledging the carer label**
- **realising that you are not just a wife or a parent; that you have become a carer**
- **meeting people in similar circumstances and with a shared understanding allows you to come to terms with it**
- **CwC increased the feeling that I was a carer. It pushed me further to that point**
- **Yes, I was a carer - and it makes you think about things**

CwC consisted of a consortium of partners comprising four carers' organisations, led by the Expert Patients Programme (EPP) with a variety of training providers. The CwC ran for two and a half years of its intended three-year but was terminated ahead of schedule when it failed to meet targets for numbers of carers participating and because of DH concerns about the costs of delivering the programme. However, CwC was well received by most carers who accessed it. Positive feedback included carers reporting beneficial impacts on their health and well-being, better access to social care support and improvements affecting those they cared for.

Evaluation and methods

The mixed-methods evaluation comprised:

- **an account of the National Team in setting up, implementing and sustaining CwC**
- **report on the success or otherwise of CwC in delivering its objectives**
- **an assessment of the impact of CwC on carers taking part in the programme evidence on the impact of CwC on the organisations contracted to deliver it**

The programme was evaluated against the following objectives: Management and governance of the CwC programme
Notwithstanding the governance structure having the potential to provide a wide range of expertise and knowledge, a lack of clarity about roles and responsibilities resulted in this structure being less cohesive and effective than was desirable. There were ambiguities and uncertainties about contracted key deliverables in resolving these which compromised effectively implementing the programme.

Programme design

A prescriptive and centrally planned approach to the programme design was taken, focussing on high quality, standardised training, drawing on relevant expertise. This comprised a flexible, modular training programme delivered by trained facilitators, using approved training materials only. Carers could access the programme through three different modes: face-to-face; online; or through 'self-study'. A set of 'generic' modules, considered suitable for all carers (aged 18+) was offered as well as additional 'tailored' modules for carers in specific circumstances or with particular types of caring responsibility.

Establishing a network of local training providers

A rigorous initial provider procurement process led to the recruitment of 32 fully or part-funded local training providers offered CwC to carers throughout England. Many having existing experience of providing training to carers. A second wave of 14 providers, based on a different tariff model of funding - on a cost per unit/carer place - was later developed in response to concerns about low carer recruitment figures. The latter system of funding appeared to result in a lower cost per carer place.

Monitoring and supporting delivery

A Management Information (MI) system, subcontracted to an external agency, was developed to monitor the performance of providers and the programme as a whole. The MI system was less effective than envisaged. Data collection was inconsistent and led to large gaps in information. This caused difficulties in monitoring and evaluating individual providers and the collective performance of the programme.

Recruitment, marketing and publicity

CwC was launched nationally, resulting in positive initial publicity. However, budget limitations made it difficult to run a high-profile, on-going, national marketing campaign. Local marketing was supported through the provision of standardised marketing templates and other guidance to local providers. A wide range of marketing strategies were used by providers, some running good marketing campaigns with others having limited experience in this field and of recruiting participants.

Milestones, outputs and costs

- **Ambitious targets were set relating to carer numbers, which individual providers and the programme overall had difficulty meeting: 27,000 were to be fully trained face-to-face, but only 5,427 were trained in this way**
- **108,000 carer places were to be provided but only 40,292 were filled**
- **An additional 10,000 carers were to be trained through self-study or online but only 1,318 accessed CwC through these mechanisms**

There was no specific target cost per carer trained or number of modules attended, but low carer numbers led to a relatively high cost per filled carer place. Initially high delivery costs became more manageable for some providers once they had established the programme, and the later tariff model had the potential to deliver CwC more cost effectively than the 'fully-funded' provision.

Supporting carers

Although target number of carers was not met, the programme succeeded in registering almost 14,000 carers, 10,238 of whom attended at least one CwC module, with over half of these being fully trained. These carers were representative of the wider population of carers, and some success was achieved in meeting targets for some particularly hard-to-reach groups.

Most participating carers gained benefits from CwC. These included:

- **learning new skills**
- **meeting other carers in a supportive environment**
- **greater knowledge of how to access support**
- **improved health and well-being**
- **help to enact their caring role more effectively**
- **more confidence**
- **identifying benefits they had not previously claimed or gain additional support/services**

Substantial minorities of carers took up new social, leisure or health activities, and (in some cases) commenced a new training course or found paid work. Well after their participation in the programme was complete, many carers reported benefits affecting their caring role.

The impact on CwC providers

Through CwC, providers offered a new form of support to carers which enabled them to: extend /enhance their range of services; develop/deepen their commitment to carers; build new partnerships; raise local awareness of carer issues; gain practical experience of carer support (intelligence about: suitable venues; workable delivery arrangements; strategies for recruiting carers; establishing referral pathways; and offering carers alternative care support). Some providers attempted to sustain CwC beyond the programme's termination date.

Many providers noted that CwC offered a new form of support to carers which was previously lacking, and emphasised the importance of finding new ways of delivering support to carers of the quality achieved by CwC in the future. The availability of the CwC programme resources and module content provides an important legacy on which future carer support can be built.

Recommendations for future training and support programmes for carers:

1: Governance systems should be transparent, with unambiguous targets, outputs and outcomes specified in contractual documentation.
2: Programmes should be flexible in terms of local delivery and responsiveness to specific carer needs.
3: Output-related funding models should be considered.

4: Effective MI systems should be put in place.
5: Innovative marketing and recruitment techniques are needed.
6: Milestones, targets and costs need to be ambitious but achievable.
7: Innovative ways of supporting carers are needed, drawing on partnerships with independent sector providers and those who support, engage with or employ carers. The plans indicated in the Coalition Government's 'Next Steps' document (HMG, 2010), provide opportunities to address this.
8: Practical issues to consider when offering support to carers should include:

- **identifying suitable venues**
- **establishing workable delivery arrangements**
- **developing strategies for recruitment and referral pathways identifying the most appropriate ways to offer alternative care support**

Some points to note when planning carer training courses

Points extracted from "Delivering Training to Carers. A practical guide based on findings from the National Evaluation of the *Caring with Confidence* programme" CIRCLE. (Centre for International Research on Care, Labour and Equalities). University of Leeds. December 2011.

CwC was designed to help carers develop a range of skills relevant to their caring roles in a seven-module training course, including:

- **practical matters (such as safe lifting techniques and administering medicines)**
- **everyday life tasks (such as managing money and domestic responsibilities)**
- **being able to have 'a life of their own'**
- **helping carers become more confident in their caring roles, to seek formal support and explore recreational/employment opportunities**

CURRICULUM

Generic Modules

Finding your way
Caring and communicating
Caring and coping
Caring and life
Caring and me
Caring and resources
Caring day-to-day

Tailored Modules

Finding your way after caring
Caring and communicating for carers of those nearing end of life
Coping after caring
Life after caring
Caring and me for carers of those nearing end of life
Caring and resources for carers of those nearing end of life
Caring day-by-day for carers of those nearing end of life
Caring for a disabled child
Caring for someone living with dementia
Caring for someone living with mental ill health

Delivering successful training involves:

Planning the training

1. **The training programme should be tailored to meet the needs of carers living in the locality. Explore fully all challenges of delivering to different groups of carers [32].**
2. **Map and assess carers' needs and existing forms of support/training.**
3. **Assess fully the achievability of milestones, targets and costs prior to implementation.**

Sources of funding and financial planning

Demonstrating that supporting carers in this manner can have a long-term positive impact on their health and well-being will help funding applications.

- **Consider staffing requirements, costs, (including their training and accreditation). For example, project manager, a project co-ordinator, and module facilitators**
- **Consider costs of delivering sessions**
- **Consider initial set-up costs (monitoring access, recruitment, course materials, delivery methods, practical considerations (refreshments, travel reimbursement [33], reminder systems for carers)**

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[32] *Ideally using Census of Population data (to establish carer prevalence in the area), supplemented with intelligence from other data sources such as from groups involved in supporting carers in the locality.*
[33] *Carers are more likely to attend training sessions if travel and alternative care costs are covered. The provision of a meal also helps.*

NB. Administration/promotional activities always cost more than envisaged!

- **Decide whether the course is free or incurs a cost to carers**
- **Ensure the ongoing delivery costs are financially viable and that these can be met for the duration of the programme**
- **Try to structure the course to agencies that might want to buy a number of training places for carers**

Monitoring access

This gathers knowledge about local carers’ needs and circumstances. It can also help gauge who is not accessing the service. All relevant details about the carers should be recorded in a brief format in a one to one meeting, the moment the carer enters the service, including: age, gender, ethnicity, employment status, and who the carer is caring for/their condition.

Recruitment

Training programmes for carers need to reach ‘hidden carers’ as well as those already engaging with services.

The CwC programme mainly recruited spouses caring for people with long term conditions recruited mainly from carers’ organisations. These were the people most likely to attend courses whereas LGBT carers and carers of people from BAME groups would only attend one module. Those caring for people with complex conditions, dementia and those near the end of life were less likely to benefit in terms of certain aspects of health and well-being and may benefit from additional support.

- **Promotional literature: information sheets, maps, contact telephone numbers for carers to seek advice**
- **Word of mouth: promotional material distributed by carers’ centres and other voluntary organisations involved in supporting carers**
- **Work with other local organisations: voluntary groups, local authorities and employers**
- **Vigorous outreach work: in order to ac cess carers from ‘harder to reach’ communities/hidden carers**
- **Use of GP and NHS referrals: request existing members of staff become a ‘carers’ champion’ (e.g. a receptionist). This can be an effective way of achieving referrals**

Highlight in promotional material the benefits for carers (a break from their busy and often stressful lives) and for those being cared for (a more informed carer).

Course materials

These should be developed by experts in the field and encourage carers to explore their own situations and concerns. CwC have these materials for general use. Materials can also be bespoke to local carers needs.

Delivery methods

There is a facilitator training programme developed for CwC which can be accessed on-line. http://www.nhs.uk/CarersDirect/carers-learning-online/Pages/resources-for-training-providers.aspx (resource inaccessible 9/1/15). Training facilitators can give them confidence to deal emotional and other issues that can arise when working with carers. If this is not possible, effective facilitators should have:

- Previous experience of delivering training
- A sympathetic, empathic approach, possibly personal experience of caring
- Sensitivity to different BAME, LGBT groups

Flexibility

- **The course should be both structured and flexible**
- **Where different sessions deal with a range of caring issues, a 'pick n choose' approach may be suitable**
- **Allow carers to attend according to individual needs**
- **Facilitators can invite explorations of individual concerns with others**
- **Delivering the course material and lead/facilitate the group allowing experienced carers to support others**
- **A tailored module specifically geared to carers in the locality, including targeted information about locally available services and support is useful**

Funding could be secured to facilitate

- **a longer term mutual support group**
- **a counselling service**
- **a helpline**
- **pathway for carers into other services.**
- **the development of an on-line support forum for its specialist target group of carers**

Practical considerations

- **Assess the practicalities of provision**
- **Ensure that the needs of target groups are considered prior to offering the programme. It is essential to tailor modules to specific carers' needs**
- **Maximise uptake by a sensible and practical schedule. That is, morning, afternoon, evening, weekend or even lunch-time sessions**
- **Reduced the length of each session from three to two-and-a-half hours if necessary**
- **Be flexible about high group numbers. small groups were regarded as 'workable'**

Identifying appealing venues

- **Comfortable and welcoming reception. Refreshments upon arrival and a meal were much appreciated by Carers**
- **Balance nice venue in an attractive location for accessibility, by public transport for e.g. some carers have difficulties in making complex travel arrangements. Ensure there is a budget to cover travelling costs incurred by carers immediately and without fuss**
- **Ideally have access to a number of different venues in the locality which can be used to cater for specific carers' needs**
- **Free car parking nearby is desirable or with parking costs refundable**
- **Evening courses a venue in a safe, well-lit location is essential**

Alternative care support

- **A budget enabling provider to refund any costs carers incurred arranging alternative care. This can be crucial in some cases offering opportunities to all levels of carers. Nearly 30% of carers said they had needed to arrange alternative support in order to attend**
- **This should be provided by 'trusted and experienced' voluntary sector groups. Staff involved in delivering CwC reported that offering alternative care was essential**
- **Ensure that carers know about the service offered in good time**
- **Carers and those cared for have good reasons for not accessing this service. These could be addressed with care**
- **When courses are established uptake increases**

Future planning

Importance of carefully managing programme delivery costs. Cost issues can arise when:

(i) modules ran below planned capacity. However please note
(ii) outreach and/or recruitment was not organised as efficiently as it could have been from the outset
(iii) management, marketing or facilitator costs were higher than anticipated

- **Some providers achieved a ‘cost per carer place’ (for a single module delivered in face-to-face sessions attended by 8-11 carers) of less than £125, including management, administrative and monitoring costs**
- **Consider from the outset long-term plans for a carer training programme. If the budget can cover the cost of alternative care, organisations should include it in their plans for providing training for carers**

A rigorous evaluation of the programme’s development, including its impact on carers’ lives, is recommended as a good way of demonstrating the course’s value and the difference it can make not just to carers but to the wider health and social care system.

A summary of benefits carers reported included opportunities provided for them to:

- **learn new skills**
- **meet other carers in a supportive environment**
- **improve their knowledge of how to access support and address issues affecting their own health and well-being in a positive way**
- **enact their caring role more effectively, with many having better access to support and services**
- **feel considerably more confident and better informed**

Six months after taking part, 44% of carers in the CWC programme said that their ability to take care of the person they supported had improved. 33% felt that the standard of care they gave was better than before they took the course. 85% reported an improvement in at least one aspect of their caring role six months after they had completed their chosen modules. A significant minority of participants reported positive outcomes for themselves as well as for those they supported. This included taking up new social, leisure or health activities and some commencing a new training course or found paid work.

Source: CIRCLE, School of Sociology and Social Policy, University of Leeds, Leeds. LS2 9JT UK
Tel: +44 (0)113 343 5003
Email: CIRCLEadmin@leeds.ac.uk
Web: www.sociology.leeds.ac.uk/circle

Appendix 2. Carers’ Evaluation Questionnaire. Melbourne “Hospital-based Group Education Programme for Carers”.

To ensure the programme is meeting your needs, we would like your impressions on how well the programme functions and how you think we could improve it. We ask if would take a few minutes to answer the following questions and answer as openly and honestly as possible.

Date: __________________

1. How did you find out about the programme?

○ health professional, e.g. nurse or social worker

○ another carer

○ flyer or brochure advertising the programme

○ other ___________________________________

2. How would you rate the length of the programme?

○ just right ○ too short ○ too long

3. Was the location of the programme suitable for you? ○ Yes ○ No

4. Was the day and time of the programme suitable for you? ○ Yes ○ No

If you answered “no”, please let us know how we could improve the location or the timing below:

5. In coming to the programme I learned about the following:

○ services and resources provided by the palliative care team

○ self-care and ways to look after myself

○ information about treatment and medications and dealing with side-effects

○ an understanding of what to expect when someone is dying

○ that I have choices about how and where to care for my family member/friend

○ medical aspects of the illness

○ that I was not alone

○ who to contact if I have any concerns

○ other, please specify ____

6. By attending the programme, I gained the following skills:

○ how to better manage stress and to look after myself

○ to communicate with my family and friends about my carer role

○ to get support and access resources when I need them

○ how to communicate better with health professionals

○ other, please specify ____

7. I gained a feeling of support by attending the programme

○ very much ○ somewhat ○ a little ○ not at all

8. The programme met your needs

○ very much ○ somewhat ○ a little ○ not at all

What could have been done better to meet your needs?

9. By attending the programme I had my questions answered

○ very much ○ somewhat ○ a little ○ not at all

10. How satisfied were you with the programme?

○ very satisfied ○ satisfied ○ dissatisfied ○ very dissatisfied

11. How satisfied were you with the facilitator of the programme?

○ very satisfied ○ satisfied ○ dissatisfied ○ very dissatisfied

12. What suggestions do you have for improving the programme?

13. Do you have any final comments or suggestions you would like to add?

Thank you for taking the time to complete this survey.

Appendix 3. Family Carers in Palliative Care: A Guide for Health and Social Care Professionals

Edited by Peter Hudson and Sheila Payne. New York & UK: Oxford University Press, 2009, 309 pages

A review by Jaime H. Goldberg, M.S.W.

Palliative care is widely known to be family centred, treating both the patient and family (defined loosely as those important in the patient's life) as the unit of care. However, operationalizing this philosophy poses practical and ethical challenges for palliative care teams, leading to disparity between the ideal of family-centred care and the quality of care that is actually delivered. In an attempt to bridge this gap, Peter Hudson and Sheila Payne offer *Family Carers in Palliative Care: A Guide for Health and Social Care Professionals*, an edited text with contributions from lead clinicians and researchers in the field that addresses the emotional, spiritual, practical, and policy issues of the caregiver role in palliative care.

This text highlights the vital role of family caregivers in the lives of those receiving palliative care, urging professionals to have a greater sense of caregiver's experience in his/her role. The book opens with an overview of effective communication strategies to use with family caregivers, emphasizing the family as an interdependent system with many inherent challenges and opportunities. While negative outcomes associated with caregiving such as psychological and physical fatigue are introduced in chapter 1 and repeated throughout the text, there is also an emphasis on the positive effects of caregiving, such as meaning-making, closer family bonds, and increased self-efficacy.

Chapter 2 urges readers to embrace a social and public health model of palliative care and palliative caregiving, focusing on the need for culturally sensitive approaches to assessment and intervention. Recognizing the importance of spiritual exploration for many patients and families facing life-limiting illness, the author of Chapter 3 implores spiritual care providers to offer evidence-based, partnership-oriented, self-reflective spiritual care. Chapter 4 focuses on a more macro-level topic, presenting numerous public policy initiatives that compensate family caregivers, some of which have specific applications for those providing end-of-life care. The unique challenges of family-centred palliative care service provision in resource-poor countries struggling with the devastation of HIV/AIDS is presented in Chapter 5, highlighting the importance of innovative training models to ensure needs are adequately addressed. Ethical and legal issues are thoughtfully addressed in Chapter 6, including some of the dilemmas that are inherent in the process of difficult decision-making and how culture affects a family's ability to openly discuss subjects of illness and death. Chapter 7 examines family caregiver satisfaction literature, concluding that satisfaction is largely dependent on caregivers' perceptions of how their needs are addressed; the author also argues that qualitative research in this area will lead to richer data.

The editors dedicate the next several chapters to family caregiver needs in various care settings, including the acute care hospital and inpatient palliative care units, home, and long-term care units. While each setting presents its own challenges and opportunities, the overarching interventions - communication, education, supportive presence, and practical resources - remain the same.

The remaining chapters focus on caregiving in specific populations, including caring for children with life-limiting illness, patients with cancer diagnoses, patients with non-malignant neuromuscular diseases such as multiple sclerosis and amyotrophic lateral sclerosis (ALS), and patients with a decline in organ systems such as congestive heart failure (CHF) and chronic obstructive pulmonary disease (COPD). There is little evidence available to guide interventions for children with life-limiting illness and the authors of this chapter emphasize the need for further research. While the chapter discussing care for those with advanced cancer highlights the need to educate caregivers about the progressive and often rapid nature of decline with malignancies, the chapter about neuromuscular diseases and organ system decline stresses the chronic and often unpredictable nature of disease trajectory.

This text would be remiss without a discussion of the post death needs of family caregivers. Chapter 14 addresses the necessity of support for bereaved family caregivers, presenting three theoretical frameworks to explain, assess, and intervene following a loss. The final chapter looks to the future of family caregiving from clinical, social policy, and research perspectives stating the importance of considering family caregivers as care recipients in need of advocacy for their often hidden work.

Throughout, the book reads like a text, focusing on the literature about a wide range of challenges related to the caregiver role as well as offering practical interventions for addressing these issues. Although repetitive, each chapter gives important emphasis to the role of communication with family caregivers through the hallmark palliative care intervention - the family meeting. The authors highlight the need for further research aimed at broadening the scope of interventions available to aid caregivers in general, and particularly in palliative care.

Although the field notes from the chapter about caregiving in resource-poor countries and the case examples from the chapter about caregiving in the inpatient setting are worthwhile inclusions, what is palpably absent in this text is the voice of the caregiver; inclusion of caregiver narrative would have helped illustrate the evidence-based findings presented throughout. A more in-depth exploration of the complexities of caregiver-patient relationships, including such themes as family conflict, abusive family relationships, and dilemmas of dependency, as well as interventions for addressing these issues, would have enhanced the text's practical and educational focus.

This book offers a significant contribution to an aspect of palliative care that is emphasized in theory but often overlooked in practice. Enhancing truly family-centred care will require partnerships among clinicians, researchers, and public policymakers to ensure high quality of care delivery.

Jaime H. Goldberg. Journal of Palliative Medicine. March 2010, 13(3): 339-340. doi:10.1089/jpm.2010.9860.
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