

Supporting carers' needs including an OSCARSS study update

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- Informal caregivers for stroke in the UK provide care worth up to £2.5 billion per year (Saka et al, 2009)
- Can come at a great personal cost to caregivers:
 - Identity; emotional well-being; physical health; social participation etc.
- Can additionally contribute to poor stroke survivor outcomes (Evans et al, 1999) or threaten sustainability of home care (Arai et al, 2001)

- Arai et al (2001) Caregiver depression predicts early discontinuation of care for disabled elderly at home, *Psychiat Clin Neurosci*, 55, pp. 379-382
- Evans et al (1991) Factors predicting satisfactory home care after stroke *Arch Phys Med Rehab*, 72 pp. 144-147
- Saka et al (2009). Cost of stroke in the United Kingdom. *Age Ageing* 38(1): 27-32.

Some experiences of informal caregivers

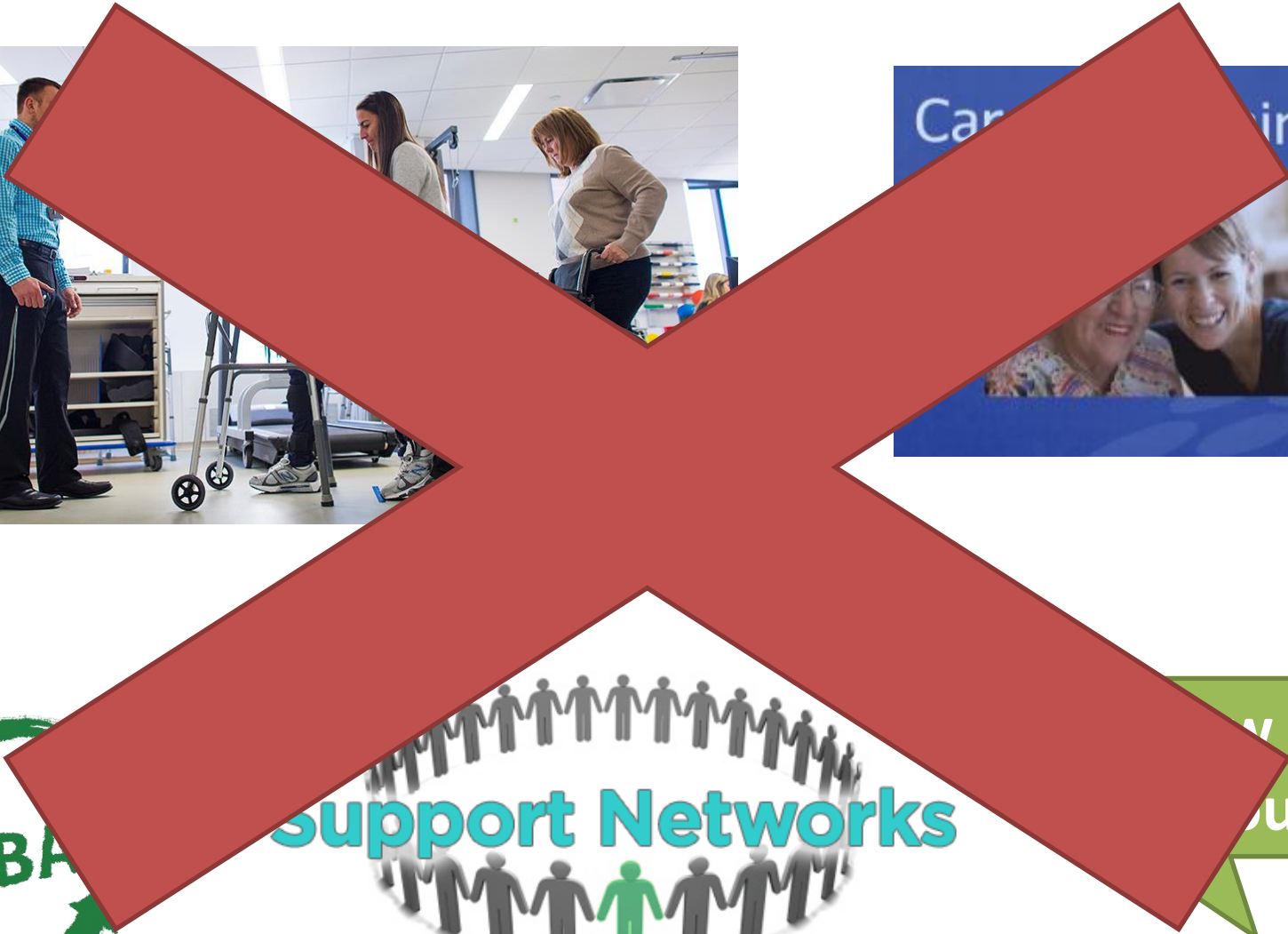
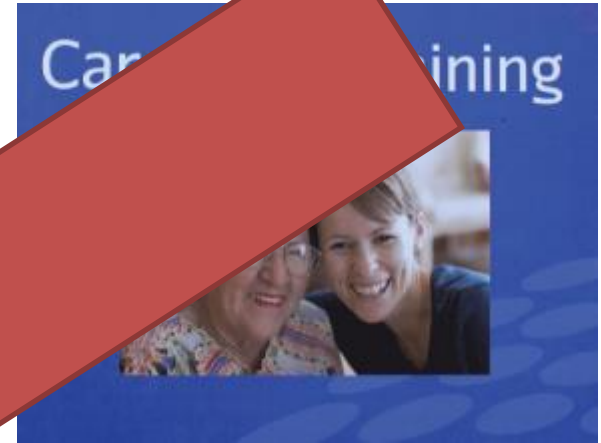


Caregiver Training



How are
you?

Some experiences of informal caregivers



How are
you?



Broadly summarised into:

Looking after
themselves

Supporting
caring role



Carer Needs – Timing it Right

Cameron & Gignac (2008). ... a conceptual framework for addressing the support needs of family caregivers to stroke survivors from the hospital to the home. *Patient Education and Counselling*. 70 (3)

Phase		Need	
Event / Diagnosis	Hospital	I: diagnosis E: talk / process	I: Information E: Emotional T: Training A: Appraisal
Stabilization		I: cause ; current care needs E: talk / process T: initial to assist with therapies	
Preparation		I: availability of resources & how to access E: anxiety / uncertainty about future; social support T: new ADL skills & rehab therapies	
Implementation	Home	I: management; impact on health / life E: anxiety for adaptation to providing care T: managing in the home incl equipment	A: Feedback on skills
Adaptation		I: participation; accessible options; planning for future E: support from others; relationships changes T: assisting SS with reintegration	

Carer Needs – Timing it Right

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Phase	Need	I: Information E: Emotional T: Training A: Appraisal
Event / Diagnosis	I: diagnosis	
Stabilization	I: cause ; current care needs E: talk / process T: initial to assist with therapies	
Preparation	I: availability of resources & how to access E: anxiety / uncertainty about future, need support T: new ADL skills & rehab therapies	A: Feedback on skills
Implementation	I: management; impact on health / life E: anxiety for adaptation to providing care T: managing in the home incl equipment	
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Needs change over time

No “one size fits all” approach

Support services for carers



- Wellbeing centres
- Exercise Groups
- GPs
- Carers Prescription

Finances, legal, housing & welfare

- Legal advice Centre
- Foodbanks
- Welfare Rights & Debt advice centre
- Advocacy
- Citizens Advice: <https://www.citizensadvice.org.uk/>
- Care and repair - <http://www.careandrepair-manchester.org.uk/>
- DWP visitation service & Benefits check

Adaptation, equipment, transport

- Personal alarms
- Motability
- Telecare
- Disabled Living Foundation
- Disability Resource Centre
- Independent Living Centre
- Assisted Living Centre
- British Red Cross
- Community transport
- Occupational Therapy



Care Act (2014)

Local Authority

- Adult services/social work
- Carers assessment
- Carers Emergency Plan

Respite & Care

- Respite Association: <http://www.respiteassociation.org/>
- Befriending services e.g. Age UK
- Headway: <https://www.headway.org.uk/>

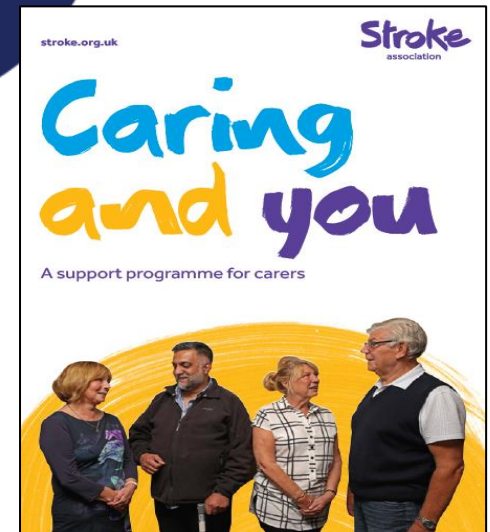
Other Support & Information

- The Association of Carers
- Back care advisor for carers
- Carers UK
- Action for Family Carers
- Care network
- Local carers support groups
- Carer training
- Carer counselling
- Carers First
- Carers information support service
- Local carer support groups
- The Carers Trust
- Carers Centre
- Crossroads (young carers)

Anything else locally?

Support services for carers

Support & Information – 3rd sector represented today



https://www.stroke.org.uk/....stroke_a_carers_guide.pdf

A current research study:

Organising Support for
Carers of Stroke Survivors

The **OSCARSS** study

Aim of OSCARSS

- 1) **develop** an approach to working with carers
- 2) **evaluate** the approach in a research project

The Approach

Developed **by** carers **for** carers



Covers the process of:

1. **Identifying** carers who might need support;
2. **Encouraging** carers to take time / space to **consider their needs**;
3. Having a **carer-led conversation** to discuss **needs & support preferences**
4. **Confirming actions** and making a plan for review

The OSCARSS Carer Research User Group

NHS

*National Institute for
Health Research*



Evaluating in a cluster RCT

35 Stroke
Association
services



- The “new approach” (N=18)
- OR
- Practice as normal (N = 17)






Then, **compare** carers outcomes in
both groups

3 months & 6 months:



Comparing carer outcomes

Postal questionnaires and telephone interviews explore:

- Their health and well-being 
- Their experiences of caring;
- Experience and impact of support received;
- Time spent providing care;
- Healthcare services used.  = 

Progress since Feb 2017:

- Recruited > 200 carers
- Collected 3 month outcomes (Primary) > 100 carers
- Collected 6 month outcomes (Follow up) > 20 carers

Planned outputs

Carer group involved in analysis and write up

- Accessible report to carer participants
- Costed, evidence-based service specification for carer needs assessment
- Journal articles: effectiveness, lessons learnt for implementation,

Find out More....

- The OSCARSS study is running in a few, participating Stroke Association services.
- <http://clahrc-gm.nihr.ac.uk/our-work/stroke/oscarss/>
- Once it is finished, the approach may be coming to a service near you!
- You can get a copy of the final report - due end of 2018/beginning of 2019.

Commissioning for carers

<https://www.england.nhs.uk/commissioning/comm-carers/principles/>

About us

Our work

Resources

Commissioning

Get involved

NHS Commissioning

Commissioning for Carers

Who is considered a carer?

Carer Facts – why investing in carers matters

What carers want

Background to developing the Commissioning for Carers principles

Commissioning for Carers Principles

Home > NHS Commissioning > Commissioning for Carers > Commissioning for C

Commissioning for Carers Principles

The Commissioning for Carers Principles focus on key actions that are more likely to achieve the desired outcomes from the evidence and case studies that have been received.

To help commissioners consider current commissioning practices with regard to carers, we could be improved, we have provided a simple self-assessment questionnaire for commissioners to rate yourself and provide an opportunity to see if there is anything existing services. Supplementary questions have been included to help trigger ideas. The intention is to help with decision making processes to support the development of services for carers.

Commissioning for carers

