

self management uk

Self Management and the Role of Carers

**Self Management UK presentation to
ADASS South East Carers' Workshop
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Self Management UK messages

- ✓ Self-management for carers and young carers
- ✓ Local Authority help for adult and young carers
- ✓ Local Authorities and health services involving carers as expert partners to develop self-management for people with Long-term conditions and their carers (who could have LTCs)
- ✓ Case studies to discuss and identify action points

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Overall theme: self management from the voice of a carer rather than policy soundbites

Self management uk

- ✓ Self management uk programmes
- ✓ Health and social care professional courses
- ✓ Carers courses updated to meet current need
- ✓ Anticipate growing need for more self-management support for 6.5m carers
- ✓ NICE Guidance #21 (*CQC Review of Home Care services*) home visits of >30 minutes

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self management uk, a registered charity, delivers and develops self-management programmes aimed at helping people living with any long-term health condition, or carer of someone living with a long-term health condition to manage their condition better on a daily basis. Our range of courses includes condition-specific programmes, young people's programmes and health professional awareness programmes.

Our carers courses – for adults and young carers- have been specially designed to support carers to improve their day to day management, consider their own health and wellbeing and confidently support the person they care for through the use of self-management tools and techniques.

Care Quality Comm review recs for NICE guidance ref longer 'time slots' for home based care we anticipate it could mean there are

- fewer paid carers
- number of unpaid carers could rise
- higher demand for un-paid carer hours to compensate for potentially re-freshed eligibility criteria for LA funded home care services

Carers stats

- ✓ Impact of caring on health: GP Patient Survey 2013
- ✓ Different offers from one local authority to another
- ✓ Carer info on entitlement versus reality of provision
- ✓ Carer frustration and anger builds
- ✓ Care Act 2014 requires LA to reduce social care need

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The vast majority of caring in the UK is via family and friends, who make up the UK's 6.5 million carers valued at £119 billion per year –more than total spend on the NHS. Around 60% of carers have a long term condition, rising to 70% if caring for someone >50hrs/wk. GP survey 2013 on carers reported higher levels of arthritis, high blood pressure, chronic back problems, diabetes, mobility problems, anxiety and depression. The offering from one local authority or CCG to another is not the same nationally. Budget cuts have further reduced the opportunity for LAs to offer whole family support to young carers. Interpretation of the Care Act varies and thus provision and access to services. Voluntary sector services dependent LA funding are highly vulnerable to budget cuts resulting in sudden reductions in carer support services. Carer support websites will state entitlements for adults and young carers but in reality the provision is different. E.g. one local authority charges carers a very large administration fee to set up a care plan for themselves and a weekly service fee to manage their care plan which is very dis-incentivising. Frustration and anger build for adult and young carers who feel undervalued.

LA compliance with the Care Act requirement that they delay, or reduce the development of people's social care needs as far as possible and work with other support agencies (inc. vol sector) in a person- centred approach to achieve this should prompt greater investment in supporting carers.

Self-management

- ✓ Impact of caring on emotional / social needs
- ✓ Skills and tools to tackle problems pro-actively
- ✓ Make time to look after own health and wellbeing
- ✓ Take more control of situation and live fuller lives
- ✓ Self-management Triangle

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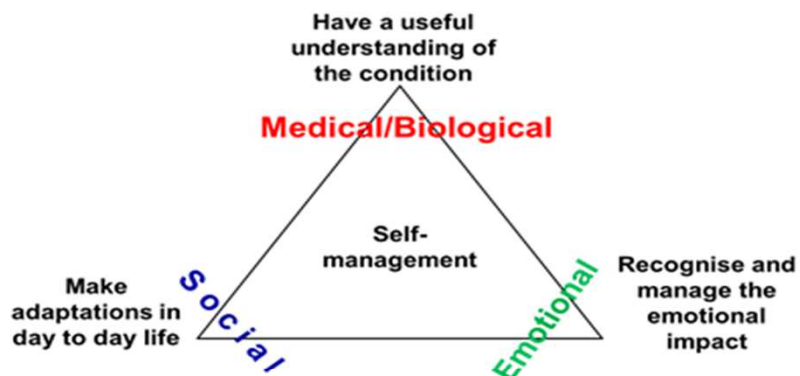
As a carer of someone with a long-term health condition, the carer is also affected by their condition, and the changes that they have to make. They also have their own needs, and have to adapt to support someone they love and care for dearly. So, this brings with it emotional and social difficulties for them to manage.

Self-Management is a term used to describe skills and tools which enable people to tackle these problems in a pro-active way. Self-Management is also about working with Health & Social Care professionals to ensure the carers needs and the needs of the people they care for are met.

Applying self-management means that by having a helpful understanding:

- of their own needs and those of the person they care for
 - being able to recognise and manage the emotional impact
 - being able and willing to make adaptations in the way things are done
- they can take back control over their lives and get into the driving seat again. However, we know that this is sometimes 'easier said than done.'

Self- Management Triangle



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- ✓ Offers tools for a better balance of life & commitments
- ✓ Ways to cope with difficult emotions
- ✓ Problem solving, assertiveness, effective communication

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The Self Management Triangle is a model of support used to offer tools for a better balance of life and commitments, ways to cope with difficult emotions (anger/frustration) and problem solving skills. The carer can deal with their anger and channel this energy into identifying what help they need and knowing where to find help. They will feel more confident to participate in service discussions to improve services for carers. The Self Management Triangle equips carers to be assertive and effective communicators and to make informed decisions about what they want or need as a person as well as what they want or need in their caring role.

Our Self Management for Life for Carers course uses this triangle as the foundation for the programme. Our course offers:

- goal setting and problem solving skills to channel their anger into identifying what help they need and knowing where to find help
- confidence to participate in discussions with health and social care professionals to improve services for carers
- tools to be assertive and effective communicators and make informed decisions about what they need as a person/ in their caring role locally.

All three corners need to balance

- ✓ Important to have useful understanding of the health condition of the person they care for, **but also**
- ✓ Working in partnership: health & social care
- ✓ Supporting themselves as a carer
- ✓ Recognise emotional impact of caring on carer
- ✓ Carer well-being and mental health is key
- ✓ Understanding need to make adaptations

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Biological / medical corner shows importance of having a useful understanding of the health condition for the person they care for, as well as understanding their own health needs. Knowing what can help to manage symptoms, steps which may help prevent deterioration or further health complications. Relates to working partnership with health and social care professionals, to ensure needs of patient and carer are met. Biological support includes, knowing what to eat, when to rest, when to exercise, understanding medication options and knowing what questions to ask.

Having a way of **managing their emotions** is essential for the carer's own well-being and mental health. It also enables them to both support the person they care for by recognising and exploring their own emotions, to consider new approaches to problems with a positive outlook.

The **social point** relates to the carer understanding the need to adapt their daily routines to allow them to care for someone, as well as the impact of the adaptations needed which will effect their life: where to live, shopping habits, employment, hobbies, socialising with friends and family.

Knowing how to correct any in-balances in the triangle is a key skill of a good self-manager.

Support for Carers – East Kent

- ✓ Royal Surgical Aid Society/Alzheimer's Society research 2013. Pilot project, East Kent: community based support for dementia carers
- ✓ Care Act 2014 :
 - more rights and entitlement for users and carers
 - wellbeing and personalisation of services
 - assess carers' needs and regardless of eligibility/signpost to sources of support
 - preventing carers developing care & support needs
- ✓ Backdrop of reducing budgets, higher eligibility thresholds but rising need for support

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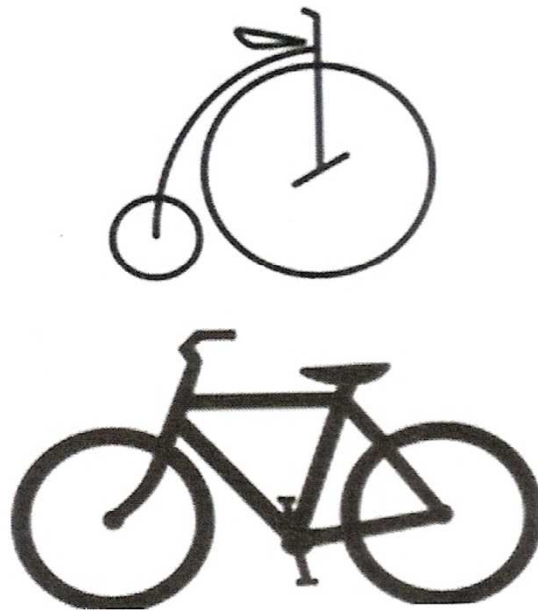
Research project 2013 RSAS stated that LAs should provide more connected service locally for carers. RSAS is now investing to develop community-based support, putting the family carers of people with dementia at the centre. Started in East Kent from April 2015.

Plan to help carers of people with dementia so they :
can support their relative to live well at home for as long as possible / have quality of life themselves, their families and person they care for,
can help their relative have active role in community/not socially isolated / contribute to the design of services/ determine what works for them.

RSAS funds services to **fill the gaps in support** for carers of people with dementia.

This example represents the Self Management Triangle working in practice.
<http://www.thersas.org.uk/east-kent-dementia-carers-project/>

Wheels of change



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Wheels of change

- ✓ Penny Farthing: not skilled, needs a lot of support
- ✓ Mountain bike (with stabilisers at times)
 - Interaction with carers for coping day to day
 - Goal setting, personal wellbeing reviewed
 - communication with health and social care teams
 - Confidence to choose to access local support
- ✓ 'Double respite' for carer and user during course

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Moving from '**Penny Farthing**' (not skilled and needs a lot of support to stay on) – may need health and social care services themselves.

Moving to '**mountain bike**' (with stabilisers at times) - carer understands themselves in their role and the challenges that caring brings whilst living with a LTC themselves.

Interaction in self management courses for carers is essential between participants + trained tutors due to social isolation, anger and frustrations they face.

When commissioning self-management support for carers consider offering 'double respite'.

Offer the course in a community setting with a room for the carers to participate but also **a room in the same building for the people that they care for** to have a purposeful use of their time, such as undertaking some self management support themselves:

- formal self management course , an opportunity to socialise , craft activity, a chair-based exercise session, healthy eating cookery sessions

Provide a cooked lunch for the carers. "Food that is made for them, rather than them making food for others".

Local Authority support for carers

- ✓ Self-management courses: cost effective, sustainable
- ✓ LA interventions don't work:
 - timing, relevance, access
 - one off-support not sustainable solution to carers' needs
- ✓ Self-management course offers carer freedom/choice
- ✓ Consistent self-management course content for quality
- ✓ NHSE Commissioning for Carers 2014 checklist # 9

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Commissioning self-management support can reap considerable budget savings and can respond to carer identified needs in carers assessment. On average for NHS primary and secondary care budgets we have found that for every £1 spent another £2.24 is saved.

Carers say that short term interventions don't work due to lack of timely access, relevance or carers lacking awareness of availability. The one off sessional support offered by social care is not a sustainable solution to carers needs. Education and confidence building for carers to ask the right question, make informed decisions and articulate the care they need is more sustainable and ultimately will result in their more efficiently using NHS and social care resources. Availability of time for carers is often seen as a problem but by providing opportunities for carers to take part in self management courses help the carer discover they can do things outside of their caring role and be more fulfilled.

NHSE Commissioning for Carers 2014 designed a checklist for health teams to identify existing carer support and whether to increase support to meet recommendations. #9 says Invest in carers to stay well themselves.

<https://www.england.nhs.uk/ourwork/pe/commitment-to-carers/> and
<http://www.england.nhs.uk/commissioning/comm-carers/>

Involving carers as expert partners

- ✓ NICE Guide 21: pro-actively gather family + carer views
- ✓ Carers valued as partners to work with GPs
- ✓ Informed and shared decisions for efficient service use
- ✓ Carers' Passport formalises involvement in pathways
- ✓ NHSE Commitment to Carers 'priority 2'

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Carers do not always choose to become carers, sometimes it just happens and they have to change many aspects of their lives to adapt to their new caring situation which can impact on the whole family. **'Think Family think carer'** slogan may help health and social care frontline staff to be more aware of the likelihood that the person attending the appointment with the patient is a carer and a connection made with them to find out their views.

Whilst services are improving it is frustrating for carers sometimes not to experience the improvements. More identification of carers and joint working between carers and **GPs** will reduce the need for repeat visits to the 'first port of call' to identify what is needed and how to access.

A Carer's Passport would help hospital teams acknowledge formal involvement of a carer in developing pathways e.g. offering subsidised parking

NHSE Commitment to Carers – May 2014 'priority 2' to train healthcare staff to identify, involve and recognise carers as experts and as individuals with their own (health) needs/choices and lives to lead. Incidentally Self Management UK runs a course for healthcare and social care to gain first hand experience of the needs of carers and learn how to improve their practise to meet carers' needs.

Local Authority carer support ideas

- ✓ Commitment to Carers 2014: NHS Vanguard sites
- ✓ Joint Carers Strategies: Family Carers Prescription Service
- ✓ DWP, Public Health, hospital discharge/re-enablement
- ✓ Ask carers what they *need*, offer holistic carer support
- ✓ Joint working : *standard* practice not best practice
- ✓ Develop products with charities to address need

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NHS Commitment to Carers 2014 suggests LAs team up with NHSE Vanguard sites offering Multispeciality Community Providers to offer localised support for patients with LTC and carers to take on a more active role in self managing their condition(s) + prevent carers developing needs for care and support themselves.

Use 'Better Care' funding to strengthen implementation of Joint Carers Strategies where they have been developed , encourage GP surgeries to expand the Family Carers Prescription Service , work with Public Health, hospital discharge and reablement teams and DWP (for a benefits check) to identify carers not on current LA/NHS lists who are at high risk of burnout and developing own care needs.

Once identified ask carers what they need and offer holistic support for their long term condition. Will help reduce their healthcare episodes and save funding.

Joint working to support carers should be standard practice not best practice to save health and social care budgets. **These ideas chime with the recent recommendations of the Carers Trust after a Freedom of Information request was sent to all councils in England to find out how councils are responding to the new duties of care in the Care Act and specifically their responsibility regarding prevention for carers.** Voluntary sector organisations such as **self management uk** are always looking for ways to respond to what service users and carers need and have adapted their training courses in response to feedback. Local authorities and voluntary sector organisations working together to develop products will help to provide the support that carers have asked for. **An Online version** of our 'Self Management for Life Carers' programme could be developed using available funding from a Dept Health, DWP and Equalities Office pilot project which wants to offer to support the voluntary sector work with families and carers to make use of assistive technologies and other approaches to ensure carers have the chance to work if they want to. We'd like to work with LAs to support carers stay in work if they wish or prepare to be 'work ready' by providing access to an online self management for carers course. See bottom of page 8 of 'The Care Act 2014 A guide to efficient and effective interventions for implementing the Care Act 2014 as it applies to carers ' for details of the £1.6 m pilot project funding offer.

<http://www.local.gov.uk/documents/10180/5756320/The+Care+Act+2014+guide+to+efficient+and+effective+interventions+for+implementing+the+Care+Act+2014+as+it+applies+to+carers/b4399478-e3fc-4be7-b204-11ca57da54da>

Case studies to discuss in 15 mins

Case studies **feedback** in 15 mins

- ✓ Identify self-management issue(s)
- ✓ Identify required action, noting:
 - Care Act 2014
 - recognition that carers are expert partners
- ✓ Identify how to implement