Interactive Dementia Masterclass for Primary Care

The needs of family caregivers

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Supporting family caregivers of people with dementia.

What would you like to discuss ??????
Professional’s attitudes towards family carers

Think about a situation where a carer has been seen as a ‘nightmare’

How were they viewed by the service?

What has led to that view?

What could have been different?
Perceptions of family carers ……

<table>
<thead>
<tr>
<th>Carers are often described negatively</th>
<th>How should we think about carers?</th>
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</thead>
<tbody>
<tr>
<td>Trouble maker</td>
<td>Invaluable</td>
</tr>
<tr>
<td>Needy</td>
<td>Hard working / dedicated</td>
</tr>
<tr>
<td>Interfering</td>
<td>‘Experts’ in their situation</td>
</tr>
<tr>
<td>Unrealistic</td>
<td>Skilful and knowledgeable</td>
</tr>
<tr>
<td>Abusive</td>
<td>Resilient</td>
</tr>
<tr>
<td>Unskilled or unable to care</td>
<td>The person who cares most of all about the person with dementia</td>
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The challenge of caring for someone with dementia

• Caring is often quite sudden, unpredictable and changeable.

• Caring requires a breadth and range of knowledge & skill that carers may not already possess.

• Caring can be overwhelming and carers need support to equip them to cope with, and adjust to caring, as they take on this challenging and emotional role.

• Carers of people with dementia experience high levels of anxiety, depression and stress yet their needs often go unrecognised.

• Caring for someone with dementia is LIFE CHANGING.
Carers experiences

Carers begin their caring journey with little knowledge and skill and will often struggle or become over anxious because they don’t know what is happening, what to do or what to expect.

Carers find it hard to look after their own health needs and often ignore them.

Carers are caring within unique life settings, they also have to deal with other secondary stressors such as marital breakdowns, problems with children, health problems, financial problems, broken families.

Carers experience overwhelming emotional reactions such as guilt, living grief, multiple losses. Carers often experience social isolation. The progressive and unpredictable nature of dementia causes additional strain.

Carers find it sometimes impossible to speak openly with professionals in front of the person.
In a systematic review of carer burden literature, Chiao et al (2015) found:

The main sources of carer burden in dementia care are grouped into 2 categories:

1. Patient characteristics
2. Caregiver characteristics

1. Patient characteristics:

Presence of behavioural and psychiatric symptoms and personality change

Poor functional ability and physical limitations of the person with dementia

The severity of the dementia, fronto-temporal dementia and long illness duration
2. Caregiver characteristics

Caregiver socio-demographical factors
- low monthly income, educational level, co-habitation with pwd and age of the carer (younger and older carers)

Psychological factors
- poor psychological health of the carer, poor perceived well-being of the carer, depressive symptoms, poor self sufficiency in symptom management, anxiety and authoritarianism

Caregiving-related factors –
- care load and poor family functioning
What do carers need?

To feel valued and recognised as partners in care to be able to use their knowledge about the person with dementia that we do not know.

To be listened to, they know the slightest change in the person with dementia and know when something isn’t right. To have the chance to have a private discussion.

Knowledge and skill, we need to up-skill carers to help them understand dementia and how to cope with difficult symptoms.

To be encouraged to care for themselves and recognise their own needs and keep well.

Carers need greater emotional, psychological and social support to prevent increasing admissions to residential care homes and hospital settings for pwd.

Carers need respite that is useful / acceptable and support to navigate the system
Carers need - what do carers need to know to equip them to care for people with dementia?

Carers need to:

- Understand the experience of the pwd
- Understand that it is not their fault, it is a physical cause
- Understand why symptoms happen and how to respond to them
- Develop a ‘box of tools’
- Understand their own emotions
- Understand their own limitations
- Learn how to perform intimate personal care and maintain health
- Know when to maintain independence
- Learn not to get into conflict
- Know where to get help
- Understand the prognosis (if they want to)
- Understand how their own responses can affect the pwd
- Know about the effects of physical ill health on dementia
- Carers need to know they can trust us and that we will listen to them.
What primary care services can do to help

• LISTEN

• A CHANCE TO TALK IN PRIVATE
  (http://www.gmc-uk.org/guidance/ethical_guidance/confidentiality_64_66_sharing_information.asp)

• ENGAGE IN A PARTNERSHIP WITH THE CARER

• ACKNOWLEDGE THEIR ROLE

• EMPATHISE WITH THEIR SITUATION

• LOOK AFTER THE CARERS HEALTH

• DONT PUT PRESSURE ON TO ACCEPT THINGS THEY DONT WANT

• REASURRE CARERS THAT EMOTIONAL REATIONS ARE NORMAL
  (although difficult)

• SIGNPOST THE CARER TO SOURCES OF SUPPORT
Sources of help for carers of people with dementia

**ADMIRAL NURSE DIRECT** – helpline manned by experienced Admiral Nurses via national charity Dementia UK - 0800 888 6678

**ALZHEIMER’S SOCIETY** – advice, support and information / **AGE UK**

**CARERS UK** – carers.uk.org – 0808 808 7777 - useful website for carers and professionals

**CARERS FORUMS** – contact your local carers forums or carers centres who may have support networks and advisory / advocacy services

**CARERS DIRECT** – helpline 7 days a week - 0300 123 1053

**CARERS ASSESSMENT** – contact social services for a carers assessment to look at carers own needs

**DEMENTIA CAFES** – look for local dementia cafes where carers and pwd can access peer and professional support

**PSYCHOLOGICAL SUPPORT** – look for local carer education workshops, self help psychological services or refer for counselling or specialist therapies if required

**BENEFITS CHECKS** – make sure people have enough money
Assessment of carer burden

General Health Questionnaire
The General Health Questionnaire, 12-item version [Goldberg and Williams 1988] is a short self-rated scale designed to screen for psychological distress in the community. It is probably the most widely used and validated self-rated instrument for detection of psychological morbidity. It takes only a few minutes to administer.

Zarit Burden Interview
The Zarit Burden Interview [Zarit et al. 1980] is a 22-item self-report inventory of direct stress to carers in caring; it was designed for carers of people with dementia and has demonstrated sensitivity to change. Being disease specific gives it primacy in the area.

Caregiver Strain Index
The Caregiver Strain Index is a tool that can be used to quickly identify potential caregiving concerns. It is a 13-question tool that measures strain related to care provision. This instrument can be used to assess individuals of any age who have assumed the role of caregiver for an older adult.
Thank you.

Any questions?