NEEDS OF FAMILY CARERS OF PEOPLE WITH DEMENTIA – A brief snapshot:

Carers experiences:

- Carers of people with dementia experience high levels of anxiety, depression and stress yet their needs often go unrecognised.
- 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 or what to do.
- 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 the GP in front of the person.
- Carer stress is often caused by: not getting a break, not understanding dementia, behavioural and psychological symptoms of dementia, not having their role recognised, having to make decisions on behalf of the person with dementia such as accessing treatments, planning for the future, accepting help, full time care.

Carers need:

- To be valued and recognised as partners in care as they know so much about the person with dementia that we do not know and they save the economy millions per year.
- 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 and help them understand dementia and how to cope with difficult symptoms.
- To be encouraged to care for themselves and recognise their own needs and so keep well.
- Carers need greater emotional, psychological and social support to prevent increasing admissions to residential care homes and hospital settings.
- Carers need respite that is useful / acceptable.
- Carers need support to navigate the system.
What can GP’s do to help:

Listen to what the carer is reporting about the person with dementia, they know them best and will report things that are a sign of change in the person with dementia. If carers feel what they report is dismissed this leads to anger and frustration.

Help the carer to recognise and look after their own health needs and help them to stay well, both mentally and physically.

Give the carer a chance to talk without the person with dementia if the person is in denial, there is GMC guidance around this.

Recognise and acknowledge the carer role and reassure the carer.

Support the carer by making timely referrals for help and support.

Key reading:

- Confidentiality guidance: Sharing information with a patient’s partner, carers, relatives or friends [http://www.gmc-uk.org/guidance/ethical_guidance/confidentiality_64_66_sharing_information.asp](http://www.gmc-uk.org/guidance/ethical_guidance/confidentiality_64_66_sharing_information.asp)
- NICE Comissioning Guidelines 2013
- NICE Quality Standard for dementia 2010
- Prime Ministers Challenge on Dementia 2020

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