

Worksheet 23:

A resource pack for people with dementia and their carers

This resource pack framework is designed around the NICE Guidance ‘Dementia: assessment, management and support for people living with dementia and their carers’ (NICE guideline, 20 June 2018).

This guideline addresses how dementia should be assessed and diagnosed. It covers person centred care and support, tailored to the specific needs of each person living with dementia. As part of this, it can help professionals involve people living with dementia and their carers in decision making, so they can get the care and support they need.

Assessment and diagnosis services

‘People living with dementia have the right to expect equivalent access to diagnosis, treatment and care services for comorbidities as people who do not have dementia.’

Name of GP Practice/Health Centre:

Telephone Number:

Name of GP taking a lead role in supporting people with dementia:

‘Memory services and equivalent hospital and primary-care-based multidisciplinary dementia services should offer a choice of flexible access or prescheduled monitoring appointments.’

Name of Memory Service:

Address:

Telephone:

Email:

Website:

List of Services offered:

Referral process:

Support services

‘Named professionals should’

- *arrange an initial assessment of the person’s needs, which should be face-to-face if possible*
- *provide information about available services and how to access them*
- *involve the person’s family members or carers (as appropriate) in support and decision making*
- *give special consideration to the views of people who do not have capacity to make decisions about their care, in line with the principles of the Mental Capacity Act 2005’*

‘Named professionals will develop a care and support plan, and:

- *agree and review it with the involvement of the person, their family members or carers (as appropriate) and relevant professionals*
- *specify in the plan when and how often it will be reviewed*
- *evaluate and record progress towards the objectives at each review*
- *ensure it covers the management of any comorbidities*
- *provide a copy of the plan to the person and their family members or carers (as appropriate).’*

Dementia Advisor Service

Address:

Email:

Telephone:

Website:

List of Services offered:

Referral process:

Admiral Nurse Service

Address:

Email:

Telephone:

Website:

List of Services offered:

Referral process:

Local Authority/Council

Address:

Telephone:

Website:

Email:

List of Services offered:

Referral process:

Advocacy Service

Address:

Telephone:

Website:

Email:

List of Services offered:

Referral process:

Activities for people affected by dementia

Interventions to promote cognition, independence and well-being:

- Offer a range of activities to promote well-being that are tailored to the person's preferences
- Offer group cognitive stimulation therapy to people living with mild to moderate dementia
- Consider group reminiscence therapy for people living with mild to moderate dementia
- Consider cognitive rehabilitation or occupational therapy to support functional ability in people living with mild to moderate dementia'

Activity provided:

List of services offered:

Might include:

Dementia Adventure: www.dementiaadventure.co.uk

Creative Dementia Arts Network: www.creativedementia.org

Singing for the Brain: www.alzheimers.org.uk/get-support/your-support-services/singing-for-the-brain

Arts for Dementia: www.arts4dementia.org.uk

NAPA (National Activity Provides Association): www.napa-activities.com/

Dementia Action Alliance: www.dementiaaction.org.uk

Referral process:

Independent, voluntary and charities sector

Alzheimer's Society:

Address:

Telephone:

Website: www.alzheimers.org.uk

Email:

List of Services offered: national organisation but with local branches.

National Dementia Helpline 0300 222 11 22. It is open seven days a week providing information, advice and emotional support to anyone affected by dementia.

Talking Point – online community: a place where you can ask questions, share experiences and get information and practical tips on living with dementia. It's free to use, open 24 hours a day, and all you need is an Internet connection.

Find support near you – a comprehensive directory allows you to find advice and information on support services. Simply enter your postcode or location.

Dementia UK: national organisation

Address:

Telephone:

Website: www.dementiauk.org

Email:

List of Services offered: Admiral Nurses, Dementia Helpline, information and advice, Admiral Nurse Dementia Helpline on 0800 888 6678 from 9am to 9pm Monday to Friday, and from 9am to 5pm during the weekend. Or send an email to helpline@dementiauk.org.

Young Dementia UK: national organisation

Address:

Telephone:

Website: www.youngdementiauk.org

Email:

List of Services offered: Information and advice for people with dementia who are under 65 years of age.

The Lewy Body Society: national organisation

Address:

Telephone:

Website: www.lewybody.org

Email:

List of Services offered: The Lewy Body Society, established in June 2006 in the UK, was the first charity in Europe exclusively concerned with Lewy body dementia. Their mission is to fund clinical research to improve the diagnosis and treatment of the disease. They also raise awareness of Lewy Body dementia among the general public and those in the medical profession and decision making positions, and provide information resources for patients and carers.

National Stroke Association: national organisation

Address:

Telephone:

Website: www.stroke.org

Email:

List of Services offered: Information and advice, particularly about Vascular dementia.

Alzheimer's Research UK: national organisation

Address:

Telephone:

Website: www.alzheimersresearchuk.org

Email:

List of Services offered: 'Alzheimer's Research UK is the UK's leading dementia research charity, dedicated to causes, diagnosis, prevention, treatment and cure. Backed by our passionate scientists and supporters, we're challenging the way people think about dementia, uniting the big thinkers in the field and funding the innovative science that will deliver a cure. Our mission is to bring about the first life-changing dementia treatment by 2025.

With your support, we're working across four key areas of action.

- Understand the diseases that cause dementia.
- Diagnose people earlier and more accurately.
- Reduce risk, backed by the latest evidence.
- Treat dementia effectively.'

AgeUK: national organisation

Address:

Telephone:

Website: www.ageuk.org.uk

Email:

List of Services offered: Information and advice.

For family carers

'Offer carers of people living with dementia a psychoeducation and skills training intervention that includes:

- *education about dementia, its symptoms and the changes to expect as the condition progresses*
- *developing personalised strategies and building carer skills*
- *training to help them provide care, including how to understand and respond to changes in behaviour*
- *training to help them adapt their communication styles to improve interactions with the person living with dementia*
- *advice on how to look after their own physical and mental health, and their emotional and spiritual wellbeing*

- *advice on planning enjoyable and meaningful activities to do with the person they care for*
- *information about relevant services (including support services and psychological therapies for carers) and how to access them advice on planning for the future'*

Good Neighbours Network: national organisation

Address:

Telephone:

Website: www.goodneighbours.org.uk

Email:

List of Services offered: 'Good Neighbours Network is a collection over 120 local groups run by local people for local people all offering a helping hand to others in their community. The groups provide both practical help, with tasks and emotional help through befriending schemes and an expanding range of social activities, from film club to bike club. Each group is unique and operates autonomously. Many offer much needed transport to medical appointments or a hand with the shopping, we have two Dementia cafes in the Network and even a football club. All of the groups aim to reach out to isolated people and deliver what is needed in their community.'

The Princess Royal Trust for Carers: national organisation

Address:

Telephone:

Website: carers.org

Email: info@carercentre.com

List of Services offered: 'The Princess Royal Trust for Carers is a network of 144 Carer Centres in the UK. The network is co-ordinated by The Carers Trust. The Princess Royal Trust for Carers was founded by Princess Anne in Glasgow in 1991.

The Princess is actively involved with the Centres and attends functions to help with fundraising as well as conferences and educational events. Each centre is an independent registered charity established with help from the Trust and funded by local authorities, social services, primary care trusts and other organisations.

Our dedicated team will provide you with support to discuss, develop and implement an emergency plan. Up to 48 hours care may be available for the person you care for in the event of an emergency.

This plan cannot cover planned events, pre-planned operations or a pre-arranged admission.

Benefits of Making an Emergency Plan are:

- Peace of mind
- You are able to choose who should be involved
- The best opportunity for the cared for person to remain in their own home
- Information about other services available
- Carers emergency cards
- Emergency support may be available free of charge for up to 48 hours'

CareUK: national organisation

Address:

Telephone:

Website: <http://www.careuk.com/>

Email:

List of Services offered: 'An advice line – 0808 808 7777. An online forum which you can join to connect with other carers to share information support and advice. An upfront guide to caring – a simple tool for carers who are new to the maze of benefits and entitlements. A looking after someone guide, which can be downloaded, is for anyone caring for family or friends. The guide outlines your rights as a carer and gives an overview of the practical and financial support available. Being heard – a self-advocacy guide to help you navigate a confusing system, get your message across and cope with **complex thoughts and emotions when you are caring. Nutrition advice to help carers to eat well and to improve the nutritional intake of the person you care for.**'