



Patient information

Dementia

Information for carers of patients who have a diagnosis of dementia

Barts Health NHS Trust is committed to becoming a dementia-friendly trust as a large proportion of our patients live with dementia. We are committed to improving the hospital experience of those living with dementia along with their carers.

This information booklet includes:

- a brief overview of dementia
- details on how to access further information about dementia
- information about what Barts Health NHS Trust has in place to support individuals with dementia and their carers
- information about what you as a carer can do to help the individual you care for whilst they are in hospital
- important information you may need to know as a carer
- contact details of some of the support services available locally.



Overview about Dementia

What causes dementia?

Dementia is caused when brain cells are damaged by specific diseases, for example Alzheimer's disease or a series of strokes.

The most common types of dementia include:

- Alzheimer's Dementia
- Vascular Dementia
- Mixed Dementia
- Dementia with Lewy Bodies
- Frontotemporal dementia (including Pick's disease)

What is dementia?

The word dementia defines a set of symptoms that may include memory loss, changes in mood and difficulties with communication, reasoning and thinking. For someone with dementia these symptoms often start off small and then begin to worsen thereby affecting an individual's ability to perform everyday activities.

Symptoms

The specific symptoms that an individual with dementia will experience are dependent on which disease is causing the dementia and which parts of the brain are being affected. Each individual will experience dementia in their own way.

Who gets dementia?

According to the Alzheimer's Society, it is estimated that there are 850,000 individuals with dementia in the UK. It is believed that there will be one million individuals with dementia in the UK by 2025. One in fourteen people aged 65 or over have dementia. The likelihood of developing dementia increases significantly with age, although it can also affect younger people. There are more than 40,000 individuals in the UK under 65 living with dementia.

Further Information about dementia

The Alzheimer's Society

The Alzheimer's Society have produced a number of factsheets on a variety of topics related to dementia and caring for someone with dementia in order to support individuals living with dementia and their carers. You can visit www.alzheimers.org.uk for further information.

'The Dementia Guide'

The Alzheimer's Society have also produced a guide with important information for those newly diagnosed with dementia and their carers. This booklet helps people understand more about dementia and the treatments, support and services available. You can request this booklet directly from The Alzheimer's Society or ask staff to request a copy from a member of the Dementia and Delirium Team.

Forget Me Not

The *Forget Me Not* document aims to improve communication, interaction and the whole patient experience. It is suitable for anyone who may have difficulties communicating for any reason. We recommend that each individual with dementia has one of these documents filled out. It provides important information about the individual, such as their likes and dislikes and things the individual may need help with. Please find the *Forget Me Not* document attached to this booklet. The individual may need support from staff and carers to fill this out.

The “carer’s plan” for carers supporting patients in hospital

Our policy, “*Carers: Recognising and Supporting Carers as Partners in Care*”, contains a carer plan that will be negotiated and agreed with you on admission if you wish to remain involved in the care of the person with dementia whilst they are in hospital.

Visiting times

As a carer you can discuss and agree hours of access with the member of staff in charge of the ward.

Carers Badge

As a carer you can request from the ward staff a carer’s badge for identification purposes if you wish to remain involved in the care of the person with dementia whilst they are in hospital. This will make you easily identifiable to staff if you are visiting beyond the normal visiting hours.

Dementia and Delirium Team

There is a Dementia and Delirium Team on site. Please ask staff if you would like more information or to contact them.

What can you as a carer do to help?

Supporting Ward Staff

Please share your knowledge with ward staff about how the dementia affects the individual and suggestions as to how the ward staff can best support that individual whilst they are on the ward.

Assisting the individual

This may include carrying out practical tasks such as personal care, helping with eating and drinking, or staying with the individual to provide support and reassurance when these tasks are being carried out by nursing staff. This may also involve support and company during the day/night. If you would like to assist the individual whilst they are on the ward you should discuss and agree specific roles and tasks with the nurse in charge and record this in the “carer’s plan”.

Sensory

Please ensure that the individual you care for has their glasses, hearing aids and dentures close to hand. Where possible, ensure that they are in working order and are being used.

Familiarity

Familiar faces and items such as photographs can provide comfort and reassurance to an individual with dementia.

Important information for carers

Looking after yourself – It is important when caring for someone with dementia that you also look after your own health and wellbeing. Try to ensure that you are taking regular breaks, eating a balanced diet and getting regular sleep and exercise. Ensure that you are still participating in the things that you enjoy, such as hobbies and interests. These will all help towards looking after your own health and wellbeing and will support you in your role as a carer.

Carer's assessment – As a carer of someone with dementia, you are entitled to request a carer's assessment from your local authority if you are delivering a substantial amount of care or if your wellbeing is being affected by your caring role. A carer's assessment looks at your role and needs as a carer, how you are managing and what support you may need. If you have received an assessment you are entitled to a review if the needs of the individual you are caring for increases, or you yourself are having difficulties continuing with your caring role. The needs of the individual you care for may be different after discharge – if so, you should contact your local authority to discuss how this may affect your carer's assessment.

Carer's Allowance – If you are 16 or over and spend at least 35 hours a week caring for the individual you may be entitled to a Carer's Allowance. You do not have to be related to, or live with, the individual you care for. Carer's Allowance is money per week to help you look after someone with substantial caring needs. The individual you care for must be awarded Personal Independence Payment (PIP), Disability Living Allowance (DLA) or Attendance Allowance (AA). To apply you can contact the Carer's Allowance Unit on 0345 608 4321 or you can visit www.gov.uk/carers-allowance. The Department for Work & Pensions and the Citizens Advice Bureau can also advise you on this.

Emotional Support – Caring for someone with dementia can be difficult and demanding at times. It is important that you receive sufficient emotional support to help you overcome the difficulties you may face. Talking about your experiences and addressing your feelings is important to help maintain your own health and wellbeing. Friends and family can provide both emotional and practical support. Your GP or local counselling services can also offer support. In many areas local support groups are available where you can talk about your experiences with people in a similar situation.

Support from available services – On the following pages there is a list of some of the support services available in the local areas to Barts Health NHS Trust that may be able to support you in your role of caring for someone with dementia.

National Helplines

- **Carers UK** - 0808 808 7777
- **Alzheimer's Society's National Dementia Helpline** - 0300 222 11 22
- **Age UK Advice Line** - 0800 169 6565

Local Support Services

Carers Support - Local Services

City and Hackney Carers Centre Prideaux House, 10 Church Crescent, London, E9 7DL Tel: 0208 533 0951 Email: info@hackneycarers.org.uk Website: www.hackneycarers.org.uk	Carers FIRST – Waltham Forest Head Office - Michael Gill Building Tolgate Lane Strood Kent, ME2 4TG Tel: 0300 303 1555 Email: info@carersfirst.org.uk Website: http://www.carersfirst.org.uk
Newham Carers Network Stratford Advice Arcade, 107-109 the Grove, Stratford, E15 1HP Tel: 0208 519 0800 Email (online contact form): www.newhamcarers.org.uk/contact-us.html Website: www.newhamcarers.org.uk	Redbridge Carers Support 12 Clements Court, Clements Lane, Ilford, IG1 2QY Tel: 0208 514 6251 Email: office@rcss.org.uk Website: http://www.rcss.org.uk
Tower Hamlets Carers Centre 21 Brayford Square London, E1 0SG Tel: 0207 790 1765 Email: enquiries@carerscentretowerhamlets.org.uk Website: www.carerscentretowerhamlets.org.uk	

Social Services - Local Authorities

Hackney Social Services 1 Hillman Street London, E8 1DY Tel: 0208 356 6262 Email: access@hackney.gov.uk Website: www.hackney.gov.uk	Waltham Forest Social Services Waltham Forest Town Hall, Forest Road, Walthamstow E17 4JF Tel: 020 8496 3000 Email: wfdirect@walthamforest.gov.uk Website: www.walthamforest.gov.uk
Newham Social Services Adult Social Care Team London Borough of Newham, Newham Dockside, 1000 Dockside Road, London, E16 2QU Tel: 0208 430 2000 Website: www.newham.gov.uk	Redbridge Social Services Aldborough Road North, Newbury Park, Ilford, Essex, IG2 7SR Tel: 0208 708 7333 Email: community.care@redbridge.gov.uk Website: www.redbridge.gov.uk
Tower Hamlets Tel: 0207 364 5005 Email (online contact form): http://webforms.towerhamlets.gov.uk/AF3/an/default.aspx/RenderForm/?F.Name=JkKOxYv6zOR Website: www.towerhamlets.gov.uk	

Alzheimer's Society - a leading support and research charity for people with all types of dementia, their families and carers

Alzheimer's Society - Hackney & City Unit 1 Ground Floor 30 Felstead Street Hackney Wick, E9 5LG Tel: 0208 533 0091 Email: hackney@alzheimers.org.uk	Alzheimer's Society - Tower Hamlets Robinson Centre Mile End Hospital 275 Bancroft Road, E1 4DG Tel: 020 8121 5626 Email: towerhamlets@alzheimers.org.uk
Alzheimer's Society - Newham First Avenue Day Hospital 103 First Avenue London, E13 8AP Tel: 0208 472 0658 Email: newham@alzheimers.org.uk	Redbridge Dementia Living Well Team Elderberries Day Centre Broadmead Road Woodford Green Essex, IG8 0AD Tel: 0208 504 2771 or 0208 708 7641
Alzheimer's Society - Waltham Forest Part Waltham Forest Resource Hub (Central) 1 Russell Road London, E10 7ES Tel: 020 8556 8171 Email: walthamforest@alzheimers.org.uk	Alzheimer's Society - Barking & Dagenham Ground Floor, Broad Street Centre, Morland Road Dagenham, RM10 9HU Telephone: 020 8517 4522 Email: bd@alzheimers.org.uk

Age UK - the country's largest charity dedicated to helping everyone make the most of later life.

Age UK East London – Hackney 22 Dalston Lane London, E8 3AZ Tel: 0208 981 7124 Email : info@ageukeastlondon.org.uk Website: www.ageuk.org.uk/hackney	Age UK East London 82 Russia Lane London, E2 9LU Tel: 020 8981 7124 Email : info@ageukeastlondon.org.uk Website: www.ageukeastlondon.org.uk
Age UK East London - Newham 655 Barking Road London, E13 9EX Tel: 020 8981 7124 Email : info@ageukeastlondon.org.uk Website: www.ageuk.org.uk/newham	Age UK Waltham Forest Waltham Forest Resource Hub (North) 58 Hall Lane Chingford E4 8EU Tel: 020 8558 5512 Email: info@ageukwalthamforest.org.uk Website: www.ageuk.org.uk/walthamforest
Age UK Redbridge Advice Centre for Older People Hainault Health Centre, Manford Way Chigwell, IG7 4DF Tel: 020 8924 6173 Email: admin@ageukredbridge.org.uk Website: www.ageuk.org.uk/redbridge	Age UK Redbridge Barking & Havering Prudential Buildings 103 Cranbrook Road Ilford, IG1 4PU Tel: 020 8220 6000 Email: admin@ageukredbridge.org.uk Website: www.ageuk.org.uk/redbridge



'Forget me not'

This form will help us to learn a little about you, and what is important to you.

By sharing this information we hope to make your stay with us more comfortable and less stressful.

Things I would like you to know about me:

My name is _____ and I like to be called _____.

I come from _____.

I was born and grew up in _____.

I worked as a _____.

The people who are important to me are _____.

Important things that have happened in my life _____.

Other Important Things



Things I need to help me to communicate:

Things I may need help with:

The information within this form will be used by everyone caring for you to try to make your time in hospital more comfortable. This may include some of the staff who visit our wards such as Porters, Catering Staff, Volunteers and Chaplains.

If you do not wish to use this form or have some information which you do not wish to share, please speak to one of the nursing staff caring for you.

Things I like:



Going to bed:

Getting up:

Things which I enjoy doing:

Things which help me to settle and relax:

Things I dislike:



Going to bed:

Getting up:

Things which I don't enjoy doing:

Things which may upset me or make me anxious:

Patient Advice and Liaison Service

If you need general information or advice about Trust services, please contact the Patient Advice and Liaison Service (PALS) on 020 3594 2040 or visit www.bartshealth.nhs.uk/pals. Alternatively please contact staff who are providing your care if you require clinical advice.

Large print and other languages

For this leaflet in large print, please speak to your clinical team.

For help interpreting this leaflet in other languages, please ring 020 8223 8934.

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Leave feedback on NHS Choices www.nhs.uk

Reference: BH/PIN/562

Publication date: Feb 2017

All our patient information leaflets are reviewed every three years

