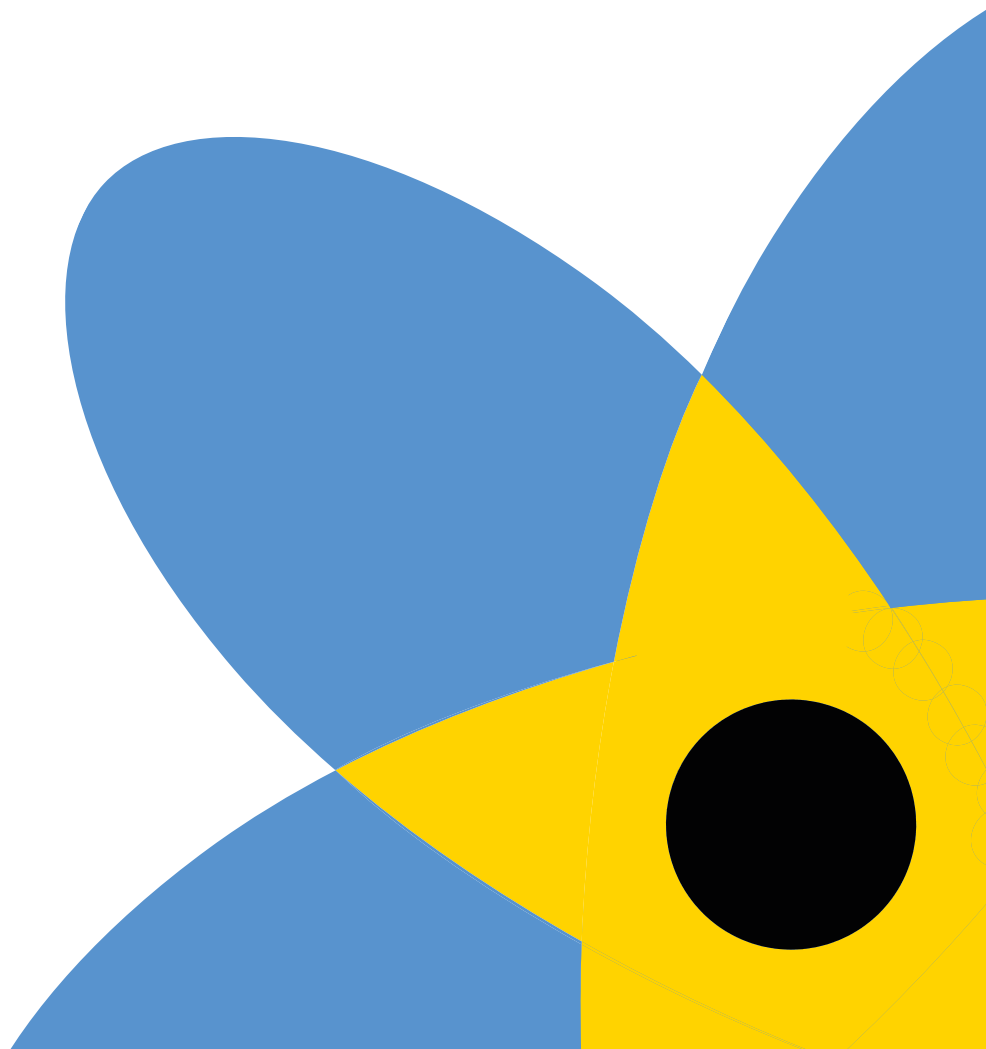


What's out there for people
with dementia, their families
and friends in York?

healthwatch
York

2017



Contents

Our aim	2
Introduction	3
What is dementia?	4
Early signs	5
Dementia myths	5
Key messages from people with dementia	6
The Dementia journey in York	7 – 11
Dementia Cafés in York	12
Charities and organisations which can help	13 – 23
York Dementia Action Alliance	24
Dementia Research	25
The Herbert Protocol	25
John’s Campaign at York Hospital	26
Useful links	27 – 28
Further suggested reading	29
About Healthwatch York	30
Acknowledgements	31
Disclaimer	31

Our aim

This guide is for people with dementia and their families and friends. We encourage you to share this with each other. We also hope it will be of interest to anyone who wants to know more about dementia.

This won’t provide all the answers to every question anyone might have. But we hope it gets you started on finding those answers. It provides information about lots of services that can help, and where to find additional information if you need to know more.

It has been developed with the support of people living with dementia in York.

If you find it useful, please let us know. If we’ve missed something, we want to know that too.

If you would rather find this information online, please go to:

www.healthwatchyork.co.uk

There you can download the guide or search our directory of services.

Introduction

Healthwatch York has been looking at how York can work better for people living with dementia, their carers and families.

Working with York Flourish Minds & Voices Forum and building on the work already done through the Joseph Rowntree Foundation, we met with a group of people living with dementia, and their carers, every month for a year.

This was a wonderful opportunity to find out about peoples' experiences, including diagnosis, family and relationships, dementia friendly spaces and places in York. Our work resulted in the publication of our report Making York Work for People Living with Dementia in March 2017 and led to the development of this guide.

The guide aims to answer a number of questions about dementia and provides information about services and organisations that can provide information and support including carers' organisations, benefits advice services, cleaning services.

We heard how important it was for people to be active and feel involved. One carer said: 'You want to feel as if you are still part of the world.' Studies have shown that positive meaningful activity for people living with dementia helps them maintain their skills, feel connected, and continue to enjoy life. This guide contains information about groups

and clubs for people with dementia and their carers including music and singing groups, reading groups, physical activity groups.

Healthwatch York helps put people at the heart of health and social care services. We want to hear from people about their experiences of health and social care services - tell us what's working well and what's not so good. We can use your feedback to make a difference.

Phone us: 01904 621133

Email us: healthwatch@yorkcvs.org.uk

**Leave feedback on our website:
www.healthwatchyork.co.uk**

What is dementia?

The word dementia describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language.

These changes are often small to start with, but for someone with dementia they have become severe enough to affect daily life. A person with dementia may also experience changes in their mood or behaviour. Dementia progresses in a way that is unique to each individual.

It is true that more people over 65 have dementia but it is not exclusively an older person's disease; younger people get dementia too.

Five things you need to know about dementia;

- ✿ **Dementia is not a natural part of the ageing process.**
- ✿ **Dementia is caused by diseases of the brain.**
- ✿ **Dementia is not just about losing your memory.**
- ✿ **It's possible to live well with dementia.**
- ✿ **There is more to the person than the dementia.**

This information has been taken from the Dementia Friends website. Anyone can become a dementia friend. It is a simple way to learn more about dementia. It also explains small actions you can take to improve life for people with dementia in York.

Find out more at:

www.dementiafriends.org.uk

www.scie.org.uk/dementia

www.alzheimers.org.uk



Early signs

Dementia can be hard to diagnose. Symptoms similar to dementia can be seen in other illnesses. It can also be difficult to tell apart dementia from the usual mild forgetfulness seen in normal ageing.

We all forget things every day, but you should visit your GP if you, or your friends and family are worried about changes in;

- ★ memory
- ★ general mental functioning
- ★ ability to carry out daily tasks
- ★ personality
- ★ behaviour

Your GP will be able to either reassure you or, if necessary, refer you to a specialist. Early diagnosis of dementia is important to allow you to get the right help and treatments and to plan for the future.

This information has been taken from:
www.alzheimersresearchuk.org

Dementia myths

- ★ **You can't drive with dementia**
False. You have to notify the DVLA that you have a dementia diagnosis but many people continue to drive after diagnosis.
- ★ **You can't work with dementia**
False. Employers should work with you to identify reasonable adjustments you might need to help you stay in employment.
- ★ **You will die of dementia within 10 years**
False. No one can say how long you will live, with or without dementia.
- ★ **You can't do the things you used to enjoy**
False. You may have to adapt what you did, but you should never give up. If you love art, music, sport, dancing, gardening or singing, you can still love them with dementia
- ★ **People with dementia all live in care homes**
False. Only one third of people with dementia live in care homes, most live in their own homes. Of those living in the community, half live on their own. One local woman living on her own with dementia writes a daily blog about her experiences:
www.whichmeamitoday.wordpress.com
- ★ **You can't talk with people with dementia**
False. You can and should continue to have conversations with people with dementia. Don't be afraid, it isn't catching, and you may even enjoy yourself!

Key messages from people with dementia

“Dementia isn’t just my problem. How you treat me can be the difference between good days and bad.”

“A little patience goes a very long way. Rushing me makes it harder, slowing down is better.”

“Don’t be afraid to talk to me - dementia is not infectious!”

“No one says it’s easy, but you can live well with dementia.”

“Since getting a dementia diagnosis, my social life has never been better!”

“Bugger off dementia - I’m still me and I’m staying!”

“Getting involved in things helps keep your brain working - don’t give up on life!”

“It reminds you to live in the moment - life is for living so get on with life!”

The Dementia journey in York

Everyone's dementia journey is unique, but the following pages provide details about where to get support and information at the various steps along the way.

Steps to take	Information
<p>Step 1 You, and/or your friends and family begin to think something has changed with your memory and/or mental functioning</p>	<p>Visit your GP, explain your symptoms and ask if you require treatment for memory difficulties. Your GP may refer you for further tests or assessments. If the GP thinks that you may have dementia then they are likely to refer you to the memory service in York (provided by Tees, Esk and Wear Valleys NHS Foundation Trust) for diagnosis and treatment. However, there are other causes of memory loss so the GP will not always refer to the memory service.</p>
<p>Pre Diagnosis</p>	<p>Dementia Forward - 01904 692473 - are a local organisation who can provide a comprehensive information and advice service about dementia. They can explain all the support available if the diagnosis is positive and provide support and assistance throughout the process with hospitals and specialists. You do not need a GP referral for this service.</p>
<p>Step 2 Diagnosis Memory Assessment and Treatment</p>	<p>If the GP refers you for diagnosis the memory service will do an initial nurse assessment of your memory prior to diagnosis by a consultant psychiatrist. A range of medical tests and investigations will be carried out to make sure the correct diagnosis and medical support is given. You need a referral from your GP to access these services. If you are given a diagnosis and treatment is prescribed the memory service will continue to monitor your memory and medication.</p>
<p>Step 3 Assessment</p>	<p>City of York Council Adult Social Care Team - 01904 555111 - can carry out an assessment to identify any practical help and support you may need. The aim is to enable you to live at home for as long as possible. Carers who have a need for support should also be offered an assessment. Ask the Adult Social Care team about a carer's assessment at the same time.</p>

Steps to take	Information
<p>Step 4 Post diagnosis</p>	<p>The following organisations can provide you, your family and carers with all the information and support to enable you to plan for your future:</p> <p>Dementia Forward - 01904 692473 Age UK York - 01904 627995 Alzheimers Society - 0330 115588</p>
<p>Step 5 Getting the knowledge</p>	<p>York Minds and Voices are designing, developing and delivering a pilot course for people newly diagnosed with dementia.</p> <p>Alzheimer's Society run caring and coping courses for carers looking after someone with dementia. This can help carers develop the understanding needed.</p> <p>Innovations in Dementia has created the Getting Along Programme which supports couples (or any caregiving partnership) dealing with a dementia diagnosis. There is a short film of this programme: www.innovationsindementia.org.uk/videos_gettingalong.htm</p> <p>Dementia Friends put on awareness sessions nationally. These can be useful for friends and family to develop a better understanding of what dementia is.</p>
<p>Step 6 Planning the future</p>	<p>Planning for your future as soon after diagnosis is very important so that you can be fully involved with any decisions being made. This will help your family and carers to know what you would like to do before your condition impacts upon your ability to inform others of your wishes. For example;</p> <ul style="list-style-type: none"> ★ Wills and Powers of Attorney ★ Benefit entitlement ★ Financial documents ★ Next of kin ★ Person(s) to contact in case of emergency for you or your family ★ Support ★ End of Life care arrangements

Steps to take

Step 7

Living well with dementia

Information

There are many charities and organisations in York which can help people with dementia to lead a positive and fulfilled life for as long as possible. Contact details for lots of organisations are listed in this guide from page 13 onwards. The organisations which can help around the time of diagnosis include:

York Flourish develop projects which help people who have dementia to live well. These include choirs, art and gardening projects, and York Minds and Voices, a forum for people living with dementia.

▶ See pages 19 – 22 for more details.

Telephone: 07905 117108

Email: info@yorkflourish.org

Age UK York/In Safe Hands can offer company to someone with dementia on short trips and outings. ▶ See page 14 for more details.

Telephone: 01904 634061

The Alzheimers Society provide local information about support, services and activities for people living with dementia in the York and Selby area.

Telephone: 01904 567701

Dementia Forward offer a range of information, advice and support for people with dementia and their carers.

Telephone: 01904 692473

Dementia Friendly Cafés. There are several cafés in York which host events for people with dementia and their carers.

▶ See page 12 for more details.

The Alzheimers Society provides ‘memories and music’ cafés in various locations around York.

See: www.alzheimers.org.uk or

Telephone: 01904 567701

Be Independent provide a wide range of telecare and telehealth equipment to help people maintain independence.

Telephone: 01904 645000

Steps to take

Information

Step 7

Living well with dementia (cont)

York Dementia Action Alliance is a group of organisations and businesses in York who are committed to making York a great city to live in and visit for people with dementia.

Citizens Advice York provide a range of support and information for people living with dementia and their carers. These include advice on benefits, money, heating etc. **Telephone: 03444 111 444**

Older Citizens Advocacy York (OCAY) provide a free and independent advocacy service for York residents aged 50 or over.

Telephone: 01904 676200

Visit your GP for reviews as needed. They are the gateway to health services. For example, for continence issues they can refer you to the continence nursing team, who can provide practical advice and support.

Step 8

Need some short term support

City of York Council Adult Social Care Team - 01904 555111 - can help if family members need some short term support with a relative who is living with dementia. They can also help if family members who are supporting someone living with dementia become unwell and/or need to go into hospital.

Step 9

Need some extra day support/24 hour care

City of York Council Adult Social care Team - 01904 555111

A social worker will assess the level of care required. They will also assess affordability and eligibility for respite and day care.

Strensall Day Care Centre is a private organisation which offers day care for adults with dementia related illnesses - **01904 490461**.

Age UK York / In Safe Hands can provide short breaks to carers and relatives caring for someone with dementia. They can also accompany someone with dementia on trips and outings. They also offer information and advice - **01904 634061**.

Home Instead provide care from a few hours a day to 24 hours a day for someone living with dementia. They also offer respite care - **01904 690884**.

Bluebird Care - 01904 691992 - are a homecare and live-in agency enabling you to continue to live at home for as long as possible.

Steps to take

Information

Step 10

Residential support

If living in your own home is no longer an option, there are many care homes in York both private and council owned which can offer both respite and residential care for people living with dementia.

City of York Council Social Care Team - 01904 555111 - can help you with making that decision and your eligibility and affordability.

They have an information booklet providing details of all care homes in York. This can be downloaded from their website here www.york.gov.uk/downloads/file/3794/care_homes_and_care_homes_with_nursing.pdf. Or contact them for a paper copy.

Alzheimer's Society produce a guide to choosing a care home. This can be downloaded from their website at:

www.alzheimers.org.uk/guidetoselectingcarehome

Step 11

Bereavement and support with loss

Talk to your GP who should offer support. Some have counselling services on site. Further counselling services include:

York Bereavement Services - 01904 725445

Cruse Bereavement Care Yorkshire (North) - 01904 481162

Email: york@cruse.org.uk

Spurriergate Centre

There are also several local psychotherapists and counsellors in York trained to support people who are suffering loss and grief. These people generally charge a fee for their services.

Support and information for carers

There are several organisations in York which can give advice and support to carers. These include;

Dementia Forward - 01904 692473

York Carers Centre - 01904 715490

York Carers Forum - 01904 422437

Crossroads Care Harrogate Craven and York - 01423 522371

Age UK York - 01904 627995

Alzheimer's Society York - 01904 567701

Dementia Cafés in York

Aroma Café Haxby

Telephone: 01904 750444

Website: www.aromahaxby.co.uk

🕒 **Monday - Saturday, 9am - 5pm.**

Last orders 4.30pm.

**Carers meetings every few months,
advertised in the café - from 7.30pm.**

Forget Me Not Memory Café, Tang Hall

Telephone: 01904 567701

Email: yorks-services@alzheimers.org.uk

Website: www.alzheimers.org.uk

🕒 **3rd Wednesday of the month, 1.30 - 3.30pm**

Run by the Alzheimer's Society.

Friday Nourish Lidgett Grove Methodist Church Acomb

Telephone: 01904 792702 / 07516 708325

Email:

admin@lidgettgrovemethodistchurch.org.uk

🕒 **Every Friday, 12 noon - 2pm**

Dementia Forward wellbeing café, Friends Together Friday, Clements Hall

Telephone: 01904 692473

Email: help@dementiaforward.org.uk

Website: www.dementiaforward.org.uk

🕒 **Every Friday 1 - 3pm. For people living with dementia their carers, family and friends.**

A dementia support advisor is always on hand to offer support and advice.

Strawberry Field Café, Field Court

Telephone: 01904 430147

🕒 **1st Friday of the month, 2pm - 4pm**

Harmony Café, St Aelreds community centre

Telephone: 07891 580128

Email: mindsinmotion@yusu.org

🕒 **Musical entertainment and buffet tea every 3rd Saturday of month, 2pm - 4pm.**

Run by Minds in Motion.

Dementia Carers Support Group - Deans Garden Centre

Telephone: 07576 746743

Email: yorks-services@alzheimers.org.uk

Website: www.alzheimers.org.uk

Bi-monthly peer led group for carers of people with dementia

Lidgett Grove Community Café

Telephone: 01904 792702

Email:

admin@lidgettgrovemethodistchurch.org.uk

🕒 **Weekly**

Café Nelli, New Earswick

Telephone: 01904 769621

🕒 **Wednesdays, 10am - 12 noon**

Greet, Eat and Meet, Clements Hall

Telephone: 01904 466086

Website: www.clementshall.org.uk

🕒 **Community lunch every Wednesday, 12 noon - 2pm. £2 per head**

Charities and organisations which can help

There are many charities and organisations in York which can help people with dementia to lead a positive and fulfilled life for as long as possible. Contact details for lots of organisations are listed on the following pages:

Arts and Crafts.....	14	Housing Advice.....	20
Advocacy.....	14	Music and Singing Groups.....	20 – 21
Befriending (suitable for people living with dementia in early stages).....	14	Practical Support.....	21
Benefits advice.....	14	Respite Care.....	21
Care homes (help to find one).....	15	Reading Groups.....	22
Carer Groups.....	15 – 16	Physical Activity.....	22
Church Services.....	16	Sensory Loss.....	22
Cleaning Services.....	16	Social Prescribing.....	23
Day Centres.....	16	Social Services.....	23
Dementia Education.....	16	Transport.....	23
Dementia Friendly Venues.....	16	Wheelchair Hire.....	23
Dementia Information and Support Services.....	17		
Driving Assessments.....	17		
Emergency Contacts.....	17		
Emotional Support.....	17 – 18		
Entertainment and activities.....	18		
Food Home Delivery Services.....	19		
Groups for People with Dementia to Attend.....	19		
Home Library Service.....	20		
Hospitals.....	20		

Activities and contact details

Arts and Crafts

Crafternoons

Tang Hall Community Centre

Telephone: 01904 431492

Email: thccmanager@gmail.com

🕒 Alternate Sundays, 2pm - 4pm

Craft Club

Tang Hall Library

Telephone: 01904 552655

Email: tanghall@exploreYork.org.uk

🕒 Saturdays, 10.30am - 12 noon

Art For Wellbeing

York Art Gallery

Email: gaby.lees@ymt.org.uk

Advocacy

OCAY (Older Citizens Advocacy York)

Telephone: 01904 676200

Email: info@ocay.org.uk

York Advocacy

Telephone: 01904 414357

Email: office@yorkadvocacy.org.uk

Care Act Advocacy Partnership York

Telephone: 01904 555111

Befriending (suitable for people living with dementia in early stages)

Age UK York/In Safe Hands

Telephone: 01904 627995

Mind York

Telephone: 01904 643364

York Neighbours (65+)

Telephone: 01904 891627

Website: www.yorkneighbours.org.uk

Offer regular phone calls

Benefits advice

Age UK benefits service (pension age only)

Telephone: 01904 627995

Citizen's Advice Bureau (York)

Telephone: 03444 111444

City of York Council Benefits Service

Telephone: 01904 552044

Email: benefits@york.gov.uk

York Carers Centre

Telephone: 01904 715490

Email: enquiries@yorkcarerscentre.co.uk

Council Tax (City of York Council)

Telephone: 01904 551558

Care homes (help to find one)

City of York Council Adult Social Care Team

Telephone: 01904 555111

Email: adult.socialsupport@york.gov.uk

Care Quality Commission (CQC)

Telephone: 03000 616161

Website: www.cqc.org.uk

Alzheimers Society

Telephone: 0300 222 11 22

Website: www.alzheimers.org.uk

Age UK

Telephone: 0800 678 1174

Website: www.ageuk.org.uk

Care homes/care homes with nursing

Website: www.carehome.co.uk/care_search_results.cfm/searchunitary/City-of-York/searchchtype/alzheimers

Carer Groups

Carers Café

Telephone: 01904 715490

Email: enquiries@yorkcarerscentre.co.uk

Website: www.yorkcarerscentre.co.uk

🕒 Spurriergate Centre

1st Wednesday of month, 10am - 11.30am

Dementia Carers Support Group - Deans Garden Centre

Telephone: 07576 746743

Email: yorks-services@alzheimers.org.uk

Website: www.alzheimers.org.uk

Bi-monthly peer led group for carers of people with dementia

York Carers Forum Meetings

Telephone: 01904 422437

Email: yorkcarersforum@tiscali.co.uk

Website: www.yorkcarersforum.org

Regular meetings at City Mills, Skeldergate

York Carers Centre

Telephone: 01904 715490

Email: samantha.ferguson@yorkcarerscentre.co.uk

yorkcarerscentre.co.uk

York Carers Centre runs 3 carers hubs - a chance for carers to get together in their local community.

🕒 Acomb Methodist Church

2nd Monday of month, 1pm - 3pm.

🕒 St Aelreds Community Centre Tang Hall

3rd Tuesday of month, 10am - 12 noon.

🕒 New Earswick

1st Thursday of month 10am to 11.30am.

🕒 Carers Centre Advice Line - Wednesday

evening 5pm - 8pm

City of York Council social services carer's assessment

Telephone: 01904 555111

Email: CarersAssessments@york.gov.uk

Website: www.york.gov.uk/carers

York Mind

Telephone: 01904 643364

Carer's monthly support group

Carers Groups

continues on the next page ➔

Alzheimers Society online forum

Telephone: 01904 567701

Website: <http://forum.alzheimers.org.uk/forum.php>

Kyra women's Project

Telephone: 01904 632332

Website: www.kyra.org.uk

Supportive services for women

Church Services

St Luke's Forget-Me-Not Services, Burtonstone Lane

🕒 **Last Saturday of each month from 11am
(Burton Stone Lane)**

Singing and prayers for people with experience of losing memories, their families and friends.

Cleaning Services

Feather Duster Cleaning (Age UK York)

Telephone: 01904 866142

Website: www.ageuk.org.uk/york/our-services/feather-duster-cleaning

Cleaning service for older people who find it hard to do their own cleaning.

Day Centres

Age UK York day centres

Telephone: 01904 627995

Strensall Day Centre

Telephone: 01904 490461

Rosevale Day Centre, Wigginton

Telephone: 01904 764242

Somerset House Day Centre, Wheldrake

Telephone: 01904 448313

Wishing Well Day Centre, Dringhouses

Telephone: 01904 337566

Dementia Education

Carer Information and Support Programme (crISP), Alzheimer's Society

Telephone: 01904 567701

Email: yorkservices@alzheimers.org.uk

Website: www.alzheimers.org.uk

Courses which provide support and information for carers

Moving and Handling of People training

Telephone: 01904 553017

Email: wdu@york.gov.uk

Website:

www.yorkworkforcedevelopment.org.uk

Courses run by City of York Council Workforce Development Unit

Dementia Friendly Venues

Krumbs café, Tanner Row

Telephone: 01904 672572

New Earswick Folk Hall

Telephone: 01904 769621

Tang Hall Community Centre

Telephone: 01904 431492

Dementia Information and Support Services

Dementia Forward - Support and Advice Service (York, Selby & the Vale)

Telephone: 01904 567701

Email: help@dementiaforward.org.uk

Website: www.dementiaforward.org.uk

Dementia forward advisors and Admiral nurse (dementia specialist nurse) provide bespoke support and advice to people with dementia and/or their carers to enable them to live well with dementia.

Driving Assessments

DVLA driver's medical enquiries

Telephone: 0300 7906806

Website: www.gov.uk

If you have a driving licence you must tell DVLA about certain medical conditions. Contact the DVLA to check if a health condition affects your driving.

William Merritt Centre Leeds (assessments in York)

Telephone: 0113 3508989

Assessments are free if referred by a healthcare professional, a fee is charged for self-referral.

Emergency Contacts

City of York Council Adult Social Services (including safeguarding)

Telephone: 01904 555111

TEWV Crisis & Home Based Treatment Team

Telephone: 01904 526582

TEWV (Tees Esk and Wear Valleys NHS Foundation Trust) All service users and their carers who are currently working with mental health services have direct access to the crisis and home based treatment service for out of hours support.

Emotional Support

Counselling & Cognitive Behavioural Therapy

Contact your GP

Cruse Bereavement

Telephone: 01904 481162

Website: www.cruse.org.uk

Dementia Forward

Telephone: 01904 692473

Email: help@dementiaforward.org.uk

Website: www.dementiaforward.org.uk

Dementia forward advisors and Admiral nurse (dementia specialist nurse) provide bespoke support and advice to people with dementia and/or their carers to enable them to live well with dementia.

Emotional Support
continues on the next page ➔

City of York Council Mental Health Support Phone Line

Telephone: 01904 673400

Mindfulness dementia Initiative

Telephone: 01904 644606

Email: susie.mackenzie@btinternet.com

🕒 **3rd Tuesday of each month.**
1.30pm - 3pm – a drop in.

1-2-1 Counselling

Telephone: 07587 155678

Email: 121counsellingyork.org

Voluntary contributions for a maximum of 6 sessions

Relate

Telephone: 01904 625971

Website: www.relate.org.uk

Individual or couple counselling. Contribution based

York Mind Counselling for Carers

Telephone: 01904 643364

Email: darrin.thomson@yorkmind.org.uk

12 free sessions

York Women's Counselling

Telephone: 01904 652706

Email: ywcs1958@aol.com

Website:

www.yorkwomenscounsellingservice.org.uk

Affordable counselling for women in York and surrounding areas

Entertainment and activities

Cinema

York City Screen

Enquiries: 01904 612940

Bookings: 0871 902 5726

Email: cath.s@picturehouses.co.uk

Website: www.picturehouses.com

🕒 **Last Monday of every month, 1.15pm.**

£4 per person, carers go free. Complimentary tea, coffee and biscuits available before the show.

Theatre

York Theatre Royal

Box Office - 01904 623568

Website: yorktheatreroyal.co.uk

Relaxed Performances - check website for details. Carers go free.

West Yorkshire Playhouse Leeds

Telephone: 0113 213 7700

Email: nicky.taylor@wyp.org.uk

Regular dementia friendly performances - usually towards the end of each run.

Relaxing space

Interactive Multi-Sensory Environment (IMUSE) - Burtonstone Community Centre.

Telephone: 01904 626965

Email: info@aamedia.org.uk

Website: www.aamedia.org.uk/index.php/what-we-do/imuse

🕒 **Sessions take place on Wednesday and Friday, advance booking is advised.**

A space where people can relax, forget the outside world and be free from anxiety.

Food Home Delivery Services

Mobile Meals (York)

Telephone: 07900 433819

Email: job1310job@hotmail.com

Fresh hot food delivered daily

Wiltshire Farm Foods

Telephone: 0800 077 3100

Website: www.wiltshirefarmfoods.com

Home delivered frozen food

Groups for People with Dementia to Attend

Minds and Voices

Telephone: 07927 405854 (Damian)
07905 117108 (Emily)

Email: dementiafriendly@outlook.com

Email: emily.abbott@herenow.org.uk

Monthly Group meetings in Acomb - normally, the last Monday of the month, 10.30am to 2pm, Lidgett Grove Methodist church.

Secret Garden Project - Rawcliffe

Telephone: 07905 117108

Email: info@yorkflourish.org

Website: www.yorkflourish.org/the-secret-garden-project

York Flourish

Secret Garden Project - Tang Hall

Telephone: 07905 117108

Email: info@yorkflourish.org

Website: www.yorkflourish.org/the-secret-garden-project

Mindfulness dementia Initiative - Lidgett Grove

Telephone: 01904 644606

🕒 Monthly meetings

Cognitive Stimulation Therapy - (Community Mental Health Team)

Telephone: 01904 556798

Rolling programme

Alzheimer's Society Service User Involvement Panel

Telephone: 01904 567701

Email: yorkservices@alzheimers.org.uk

Website: www.alzheimers.org.uk

Monthly forum for people with dementia to share their experiences

Live Well with Dementia

Telephone: 01904 567701

Email: yorkservices@alzheimers.org.uk

Website: www.alzheimers.org.uk

Run by Alzheimer's Society - group sessions for people in the early stages of dementia. Various dates/times throughout the year

Women with Dementia Club, Tang Hall

Telephone: 07725 173698

🕒 3rd Wednesday of the month,

11am t- 2pm at Burnholme Social Club

Younger Peoples Group

Telephone: 01904 567701

Email: yorkservices@alzheimers.org.uk

Website: www.alzheimers.org.uk

🕒 Monthly - last Wednesday of each month with times and venues varying.

Run by Alzheimer's Society.

Home Library Service

Home Library Service

Telephone: 01904 552655
07469378205

Email:

natasha.mort@royalvoluntaryservice.org.uk

Website: www.exploreyork.org.uk/
reference/home-library-service

Delivers books to your door

Hospitals

York Teaching Hospital

Telephone: 01904 631313

Bootham Park Hospital - Memory Clinic

Telephone: Bootham Park reception:
01904 556900

Direct:

01904 556741

Housing Advice

Alice Walker

Telephone: 01904 554095

Specialist housing advisor for older people

KJ Read Mobile Optician

Telephone: 07717 192012

Email: kim@york-mobile-optician.co.uk

Website: www.york-mobile-optician.co.uk

Music and Singing Groups

York Dance Café, Clementhorpe

Telephone: 01904 567701

Email: yorkservices@alzheimers.org.uk

Website: www.alzheimers.org.uk

🕒 **2nd Tuesday of month 1.45pm - 3.30pm at
Clement's Hall.**

Run by Alzheimer's Society

Songbox For Seniors - Haxby

Telephone: 01904 634390
07855126408

Website: www.york-songbox.co.uk

🕒 **Every Friday afternoon - Oaken Grove
Community Centre, Haxby, 1pm - 2.30pm.**

£4 per session.

Vocal Flourish Choirs

Telephone: 07905 117108

Email: info@yorkflourish.org

Website: www.yorkflourish.org

Supportive, accessible choirs – All welcome,
especially people with dementia and their carers

Singing For The Brain

Telephone: 01904 567701

Email: yorkservices@alzheimers.org.uk

Website: www.alzheimers.org.uk

🕒 **Woodthorpe - Monday, 10.30am - 12 noon
St James the Decon Church Hall,
Sherringham Drive.**

🕒 **New Earswick - Thursday, 1.30pm - 3pm
New Earswick Folk Hall,
Hawthorne Terrace.**

Run by Alzheimer's Society

Musical Connections

Telephone: 07717 177212 / 07714 821446

Website: www.musicalconnections.org.uk

Weekly sessions run by Alzheimer's society in City of York Council care homes

Practical Support

The Able Label

Website: www.theablelabel.com

Women's clothing designed to make dressing easier

Radar Keys

Telephone: 0207 2508191

Email: shop@disabilityrightsuk.org

Website: www.disabilityrightsuk.org

Allows you access to over 9,000 locked disabled toilets around the UK

York handyperson service

Telephone: 0345 3664401

07848 011260

Website: www.yorkshirehousing.co.uk/home-improvement/york

Handyperson service operated by Yorkshire Housing in partnership with City of York Council. Can assist home owners and private tenants.

Telecare/Warden Call - Be Independent

Telephone: 01904 645000

Website: www.beindependent.org.uk

A telecare and equipment service that helps people manage their lives and stay independent in their own homes

York Neighbours

Telephone: 01904 891627

Website: www.yorkneighbours.org.uk

Help with one off jobs.

Respite Care

Age UK in Safe Hands, York

Telephone: 01904 627995

Respite Care

Age UK day clubs, York

Telephone: 01904 627995

Respite Care

Crossroads Care

Telephone: 01423 522371

Website: www.crossroadsnorthyorks.org

Home based, direct support services to unpaid carers and the people they care for

Strensall Day Centre - Private

Telephone: 01904 490461

Day care for people living with dementia

Rosevale Day Centre - Wigginton - Private

Telephone: 01904 764242

Day Care/respice care for people living with dementia and their carers

Somerset House Day Centre, Wheldrake

Telephone: 01904 448313

Respite Care

Wishing Well Day Centre - Dringhouses

Telephone: 01904 337566

Respite Care

Reading Groups

Read and Reminisce Together

Telephone: 01904 567701

Email: yorkservices@alzheimers.org.uk

Website: www.alzheimers.org.uk

🕒 **2nd Wednesday of the month, 10.30am to 12, for people with dementia and their carers, York Explore Library, York.**

Run by Alzheimer's society

Physical Activity

HEAL City of York Council

Telephone: 01904 553377

Email: yorwellbeing@york.gov.uk

Website: www.york.gov.uk/info/20244/sport_and_physical_activities/431/heal_programme

Exercise referral scheme (via health professional) throughout York

Moving More Often

Telephone: 01904 551557

Sheltered housing activities open to the community

Boccia and Easy Sport (New Earswick)

Telephone: 01904 567701

Email: yorkservices@alzheimers.org.uk

Website: www.alzheimers.org.uk

🕒 **Monthly - first Wednesday of each month from 2pm to 3.30pm at New Earswick Bowles Club, Huntington**

Run by Alzheimer's Society.

The Secret Garden Project

Telephone: 07905 117108

Email: info@yorkflourish.org

Website: www.yorkflourish.org

Run by York Flourish

Eng-AGE Activities

Telephone: 01904 553377

Email: yorwellbeing@york.gov.uk

Website: www.york.gov.uk

Run by City of York Council

Energise York

Telephone: 01904 552424

Email: energise@york.gov.uk

Website: www.energiseyork.com

Friendly Energise staff are always ready to help

Sensory Loss

Resource Centre for Deafened People

Telephone: 07523 917586

Email: rcdpyork@btconnect.com

Wilberforce Trust

Telephone: 01904 760037

Website: www.wilberforcetrust.org.uk

York Blind and Partially Sighted Society

Telephone: 01904 636269

Email: enquiries@ybpps.org

Website: www.ybpps.org

Social Prescribing

Ways To Wellbeing

Telephone: 01904 621133

Email: waystowellbeing@yorkcvs.org.uk

Website:

www.yorkcvs.org.uk/ways-to-wellbeing

Connects people, via their GP, to non-medical activities, services and groups that can support their health and wellbeing needs

Social Services

Social Care Assessment/carers assessment

Telephone: 01904 555111

Hospital social services

Telephone: 01904 551673

Transport

Haxby Helpers

Telephone: 01904 750266

Free transport for people in Haxby and Wigginton

York Dial and Ride

Telephone: 01904 411282

Email: dial&ride@york.gov.uk

Website: www.yorkwheels.org.uk

A flexible door-to-door bus service for people who have difficulty getting around

York Wheels

Telephone: 01904 630080

Email: info@yorkwheels.org.uk

Website: www.yorkwheels.org.uk

Wheelchair Hire

Age UK (Tang Hall)

Telephone: 01904 411282

One size wheelchair, £10 a week - (check).

Be Independent

Telephone: 01904 645000

Various sizes, £20 per week + VAT

British Red Cross

Telephone: 01904 691021

Shopmobility York

Telephone: 01904 679222

Email: info@shopmobilityyork.org.uk

Website: www.shopmobilityyork.org.uk

Hires out electric scooters, wheelchairs and manual wheelchairs

York Dementia Action Alliance

York Dementia Action Alliance was established in 2013. It developed from a Joseph Rowntree Foundation action research project called 'Dementia Without Walls'.

The researchers worked with local people with dementia and their families to find out what living in York means to them. In particular what makes life good and what makes it more difficult. Now, a range of diverse partners from business, statutory and voluntary organisations who supported the Dementia Without Walls have formed York's Dementia Action Alliance. The Alliance welcomes new partner organisations who are committed to improving the lives of people with dementia.

Aims:

- ★ **To make York a good place for people with dementia to live and visit.**
- ★ **To bring people together as allies to support, encourage and inform each other in the aspiration to make York a dementia friendly city.**
- ★ **To be mindful of the values and standards, as per the recognition process for dementia friendly communities, ensuring that they are threaded through all changes made.**
- ★ **To increase natural support within the community for people with dementia and their carers.**

- ★ **To raise awareness and reduce stigma of dementia through learning and support networks thereby promoting inclusion.**
- ★ **To enable people to live the life they want to live.**

If you would like to be part of making a change to the lives of people living with dementia in York you can get involved and become a member of the York Dementia Action Alliance.

To join the DAA please contact Helen Mayor on: 01904 621133.

Members will be given a logo to display to show their commitment. Periodically the steering group may contact you to discuss how you are doing and offer any support. You will also be invited to York DAA meetings periodically, and receive the newsletter.

Dementia Research

Join Dementia Research

The National Institute for Health Research (NIHR) in partnership with Alzheimer Scotland, Alzheimer's Research UK and Alzheimer's Society have developed Join Dementia Research, a service which allows people to register their interest in participating in dementia research and be matched to suitable studies.

Everybody now has that chance to see what dementia research is taking place, both in their local area and across the nation.

The service delivers new opportunities for people to play their part in beating dementia; connecting researchers with people who want to participate in studies.

For more information, visit:

www.joindementiaresearch.nihr.ac.uk

The Herbert Protocol

The Herbert Protocol encourages carers, families, friends and neighbours to hold information about a person with Dementia to help the police find them quickly if they go missing.

The national scheme, which has been adopted by North Yorkshire Police, uses a form to record vital information such as a description of the person, their favourite places and the medication they are taking.

The form is filled in by the person with Dementia, their family or carers. It should be kept up to date with a recent photograph of the person. The completed form is kept safely by carers, family or friends, where it can be found quickly if the person goes missing. The police will only ever ask for the form if the person is reported missing.

If the person with Dementia does go missing, families and carers call 999, ask for the police and tell them that they have a Herbert Protocol form. The police will be able to use the information on the form to help find the missing person and return them to safety as quickly as possible.

For more information and to download a Herbert Protocol form visit: www.northyorkshire.police.uk/herbertprotocol

Forms can also be picked up from local police stations.

John's Campaign at York Hospital

John's Campaign – for the right to stay with people with dementia

York Teaching Hospital NHS Foundation Trust has signed up to a national campaign, which confirms its commitment to improving the experience of patients with dementia and their families when they are in hospital. Hester Rowell, Lead for Patient Experience said: “We know from feedback we have received that a stay in hospital can be particularly disorientating for a patient with dementia.”

John's Campaign was founded after the death of Dr John Gerrard in November 2014, by his daughter Nicci. She believes her father, who suffered from Alzheimer's, would have benefited greatly if she had been able to stay with him during his time as an inpatient.

Nicci now campaigns nationally for the right of carers of patients with dementia to be able to stay with their loved ones while they are in hospital.

Emma George, Assistant Director of Nursing, and the Trust's Lead for Dementia Care said: “We recognise the importance of listening to and involving carers when someone with dementia is in hospital as we know it leads to improved experience, quality of care and outcomes.

We are promoting John's Campaign with staff across all our hospitals to gain their commitment to making carers feel welcome and supported. Carers will be offered the

flexibility to be with the patient when they are most needed, and this may often be outside of our regular visiting hours.”

To find out more about John's Campaign visit: www.johnscampaign.org.uk

This Is About Me

We encourage all patients with dementia, together with their carers, to complete the ‘This Is About Me’ document. This tells our staff about their needs, preferences, likes, dislikes and interests. It enables our staff to understand the person better as an individual and deliver care that is right for them. It can also help to avoid problems with care or communication.

Forget-Me-Not Symbol ★

We offer the forget-me-not symbol above a patient's bed to indicate to all staff that they have dementia. This should prompt staff to look for the ‘This Is About Me’ document and to proactively engage with any carers. We will ask for consent before using the symbol.

If you have any questions or concerns about your loved one's care please ask to speak to the nurse in charge of the ward, sister/charge nurse or matron. We will always listen and try to help. If you are still having problems you can also speak to a member of our **Patient Advice and Liaison Service (PALS)** on **01904 726262** or at **pals@york.nhs.uk**.

Useful links

DEEP - The Dementia Engagement & Empowerment Project (DEEP) brings together groups of people with dementia from across the UK.

Website: www.dementivoices.org.uk

DEEP also produce useful information guides for people living with dementia and for organisations who work with people living with dementia - including one on language which everyone should read

Websites: www.dementivoices.org.uk/resources/deep-guides

www.dementivoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf

Innovations in Dementia - a community interest company that develops and tests ideas to enhance life for people with dementia.

Their website includes resources and ideas that support the creation of dementia friendly places.

Websites:

www.innovationsindementia.org.uk

www.innovationsindementia.org.uk/projects_communities.htm

York's Safeguarding Adults Board

We believe that everyone has the right to live their life free from the experience, or risk of experiencing abuse and neglect, so they are able to maintain their own independence and wellbeing. For more information:

Website:

www.safeguardingadultsyork.org.uk

If you think someone you know is being abused or neglected you should tell someone you trust. To report a safeguarding concern:

- Contact adult social care, **telephone: 01904 555111** (office hours) or **fax: 01904 554055**
- Hearing impaired customers can use the **text facility: 07534 437804** and **generic fax number: 01904 554017**
- Out of hours, **telephone: 01609 780780**

Useful links

continues on the next page ➔

Useful links (cont)

Health Education England - Finding Patience

The number of people with dementia of Black, Asian and Minority Ethnic (BAME) origin is expected to rise significantly – a seven fold increase over 40 years compared to a two fold increase in the number of people with dementia across the whole UK population in the same period.

‘Finding Patience’ has been developed with input from experts across the system and follows Patience and her family as they recognise and come to terms with her dementia and ultimately seek help.

Understanding the cultural heritage of individuals living with dementia, enables high quality, safe, person centred care that focuses on the individual rather than the disease, and an understanding of challenges that may be rooted in a person’s cultural background.

‘Finding Patience’ opens the door for health and care professionals to start talking about cultural sensitivities that may result in a reluctance to come forward and talk about concerns. It aims to encourage health and care professionals to break down barriers in order to reach people who may otherwise go undiagnosed or struggle in isolation to provide care within family units.

It is also a resource for the African Caribbean community to help raise awareness and reduce some of the stigma surrounding dementia and encourage those who may have concerns about either themselves or a family member to seek early support.

You can watch Finding Patience here:

www.youtube.com/watch?v=Q7zJL8nPqFg&feature=youtu.be

Or use this shorter link:

www.tinyurl.com/HEE-FindingPatience

Free Dementia Carer Resource – ‘Teabags in the Fridge’

There is a new video resource to demonstrate the experience of family carers for people with dementia, funded by the Yorkshire and Humber Strategic Clinical Network. It is now available and free to download:

www.dementiacarer.net (click on ‘Teabags in the fridge: learning resources’ button in the top right hand corner of webpage).

The films have been developed by Arc Research and Consultancy Ltd and have been based on information gathered from over 100 carer interviews carried out as part of the development of **dementiacarer.net**.

For more information please contact:

Tom Chrisp on **07527448551** or **tomchrisp@breakfast.solis.co.uk**

Further suggested reading

Reading Well Books on Prescription helps you understand and manage your health and wellbeing. This includes information and advice, living well with dementia, support for families and carers, and personal stories.

See more information here:

www.reading-well.org.uk/books/books-on-prescription/dementia or ask at your local library for more details.

Titles include:

Dancing with Dementia

Christine Bryden

ISBN: 9781843103325

Dear Dementia

Ian Donaghy

ISBN: 9781874790860

About Dementia: For People with Learning Difficulties

Karen Dodd, Vicky Turk, Michelle Christmas

ISBN: 9781904082903

Dementia Positive

John Killick

SBN: 9781908373571

About Healthwatch York

Healthwatch York helps you influence local health and social care services - hospitals, care homes mental health services, GP surgeries, home care services and others.

Healthwatch York will help you and your family get the best out of your local health and social care services. You can be involved in shaping these services according to what your community wants or needs.

We want to put you at the heart of health and social care services in York. We:

- ✿ Provide information about local services to make sure you know how to access the help you need
- ✿ Signpost you to independent complaints advocacy if you need support to complain about a service you've received
- ✿ Listen to your views about local services and make sure these are taken into account when services are planned and delivered. We want to know what is working well, and what isn't

Healthwatch gives us the opportunity to create a health and care system that really meets our needs.

Contact us:

Freepost RTEG-BLES-RRYJ
Healthwatch York
15 Priory Street
York YO1 6ET

Telephone: 01904 621133
07779 597361 - use this if you would like to leave us a text or voicemail message

Email: healthwatch@yorkcvs.org.uk

Twitter: @healthwatchyork

Find us on Facebook

Website: www.healthwatchyork.co.uk

Visit our website and leave your feedback about local services

York CVS

Healthwatch York is a project at **York CVS**. York CVS works with voluntary and community groups in York. York CVS aims to help these groups do their best for their communities, and people who take part in their activities or use their services.

healthwatch
York

Acknowledgements

With grateful thanks to the organisations who helped make this possible:

York Flourish and **Minds and Voices** for helping us start the conversation with people with dementia, to understand what they wished had been available to them when they started their journey.

Dementia Forward for sharing details of a wide range of support organisations that can help people with dementia and their families

Alzheimer's Society for details of all their activities.

The **Salford Dementia Champions Group** for sharing their dementia journey in Salford document and allowing us to copy their work in describing the dementia journey in York.

To our **Healthwatch York volunteers**, particularly **Fiona** and **Louise** for supporting this work every step of the way

And most importantly to the members of the **Minds and Voices** group, supported by **York Flourish**, who have given their time, energy and enthusiasm to working with us. This included people living with dementia, and those caring for them. They shared their best and worst experiences with us, their frustrations and their triumphs, so that together we can make York better for people with dementia.

Thank you **Eric and Elaine, Peter and Avril, Eddy, Charlie, Liz, Peter, Paul, Eileen, Rita and Dave, Pete and Chris, Ray and Pauline, StJohn, George and Pat.**

Disclaimer

Whilst every care has been taken to ensure that information contained in this guide is accurate at the time of printing, Healthwatch York cannot accept responsibility for any errors or omissions. Wherever possible we have checked information with relevant organisations.

Information is up to date as of May 2017.



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