### Alzheimer's Society Innovation Team are proposing to develop a 'Dementia Journey Map'

During our <u>Uniting with General Practices Project</u>, we have spoken with 115 people about their experiences and knowledge of General Practices supporting people affected by dementia. Based on what we have learnt, we invited those involved to help develop solutions to meet the identified challenge:

'How we can help General Practice to better support people affected by dementia and identify pathways to further support?'

We heard the following from GP's:

'I don't have the knowledge to signpost or refer my patients to local dementia support services. I know giving a patient who is in their 80's, the website address of a supporting organisation may not be helpful to them, but I don't know what else is available and don't have time to find out.'

'When you are training GPs and General Practice staff, lectures don't work... you need to do something to help staff to get into the shoes of people living with dementia and their families.'

'Many other GPs need to be taught how to present information about a diagnosis... they need to be taught how to "walk with" the person with dementia.'

'We are generalists... we oversee the management of people's conditions... we aren't coordinators of support.'

'I Know nothing about local services or national. I Know that Alzheimer's Society exists and they do research, but nothing else"

'There isn't a clear pathway for people pre-diagnosis to the end of life, I do refer patients to the memory assessment service, but waiting times are long. Then I don't know what happens next, I need to know who does what and when.'

We hope that the **Dementia Journey Map** could help General Practices with some of the challenges they are facing and, also benefit people affected by dementia by providing an overview of what to expect from Primary Care throughout their journey.

Here we will share with you our plan for the contents of the **Dementia Journey Map**, which includes suggestions from GP's, health professionals and stakeholders working in this area and importantly people affected by dementia.

The **Dementia Journey Map** is intended to be a concertina style folded leaflet, which opens out. One side contains the journey and the reverse side contains information about how the Dementia Journey Map can be used and where to access further support and information.

Please help us by completing <u>one</u> of the following two short surveys, they should take approximately 15 minutes:

- Survey for people affected by dementia here
- Survey for General Practice and professionals working in this area here

Your honest feedback will help determine if the Dementia Journey Map would be useful and what the impact could be on both General Practice and people affected by dementia.



# **Dementia Journey Map**

Following NHS England Transformation Framework 'The Well Pathway for Dementia'

#### **Preventing Well**

Risk of people developing dementia is minimised.

#### **Diagnosing Well**

Timely accurate diagnosis, care plan, and review within first year.

#### **Supporting Well**

Access to safe high-quality health and social care for people with dementia and carers.

#### **Living Well**

People with dementia can live normally in safe and accepting communities.

#### **Dying Well**

People living with dementia die with dignity in the place of their choosing.



#### What to expect

- Promotion of healthy lifestyle choices
- Discussion of dementia risk factors and how to reduce risk
- Managing long term conditions

#### **Further help**

British Heart Foundation

Stroke Association

Diabetes UK

NHS websites

## Steps in diagnosing dementia Role of GP

- takes patient's history,
- blood and urine tests,
- brief cognitive testing

..if dementia still suspected...

## Referral to specialist dementia diagnostic service\*

- Further history-taking
- Further cognitive testing
- Brain scan if needed

Return to GP for follow up discussion about diagnosis, care planning, consent to share information and referral to support services.

#### **Core Elements of a Care Plan\***

- Diagnosis review
- Effective carer support
- Medication review
- Evaluate risk
- New symptoms inquiry
- Treatments and support
- Individuality
- Advance care planning
- \*from NHS England Dementia: Good Care Planning
- \*Expected national average time from GP referral to initial assessment of dementia 6 weeks (although this may vary locally)

#### What to expect

#### **Information** about:

- dementia diagnosis,
- possible medication
- non-drug treatments
- support / activity groups

#### Support

- named coordinator of care
- develop care and support plans reviewed regularly
- support networks for carers / family

#### Advice on:

- rights, benefits, driving
- planning ahead
- research participation
- Other social care and voluntary/third sector support

#### What to expect

Help to maintain independence and community relationships

- Ongoing support for people with dementia, carers / family
- Staying healthy and active
- Coping with memory loss
- Technology aids
- Dementia-friendly environments
- Advice on transfer between care settings
- Choices in living arrangements

#### What to expect

- Collaborative decision-making
- Choice of palliative care setting
- Support for social, practical, emotional, physical and spiritual needs
- Family support

## REFER TO DEMENTIA CONNECT email xxxxxxxxxxx or call xxxxxxxxxxxx

Referral to Dementia Connect can be made by either a GP, self-referral, family / carer, social services

Dementia Advisor makes contact within 5 days to complete a comprehensive assessment of needs and develop a support plan



**DRAFT** 

# The Dementia Journey Map can help

- People affected by dementia
- General Practice
- Health Professionals

It can be used to support conversations between a person affected by dementia and their GP and other health professionals.

It explains some of what to expect throughout NHS England Well Pathway for Dementia.

There may be various healthcare professionals and organisations involved along the dementia journey.

This journey map can help guide you through what might happen next and who can help.

Everybody's journey is unique and may vary from the steps in the map, this is a general guide.

# Tips for GPs and other health care professionals

The Dementia Journey map has been developed based on:

NHS England Transformation Framework – The Well Pathway for Dementia

The Dementia Care Pathway Full Implementation Guidance - The National Collaborating Centre for Mental Health

NHS England Dementia: Good Care Planning

#### NICE Guidelines:

Dementia assessment, management and support for people living with dementia and their carers

Prime Minister's Challenge on Dementia 2020: Implementation Plan (2016)

# Dementia Connect: Specialist Telephone and Face to Face Support

Connect Dementia is Alzheimer's Society's new support personalised and advice service. It's for people with all types of dementia, their families and carers. The service is free and easy to access by phone or online. It puts people in touch with dementia experts, who will listen and help with all their dementia-related questions. connecting them to the support they need. This includes help in their area, as well as telephone and online advice and information.

Alzheimer's Society will keep in touch with people, so they always have the support they need, only ever needing to tell their story once.

Alzheimer's Society Side by Side is available through Dementia Connect. Side by Side matches people with dementia with dedicated volunteers, enabling them to keep doing the things they love. Also gain access to our national helpline, our online community 'Talking Point', and expert information on our website.

## Dementia Connect: Self-Management Services

#### **Dementia Helpline:**

#### **XXXXXXXXXXXXX**

The Helpline provides information, support and guidance to anyone affected by dementia regarding dementia care, health and social care and legal and welfare rights. It is open 7 days a week.

## Dementia Talking Point: Web address

Our online community is a safe space where people can ask questions, share experiences and get information and practical tips on living with dementia. It is open 24 hours a day.

#### **Dementia Directory:**

#### Web address

Our comprehensive online directory allows people to find support services, groups and activities close to them. Simply enter a postcode or location to find their nearest service.

# Dementia Information and Publications:

#### Web address

Our wide range of publications and information online will help people understand dementia.



Front Page

# Dementia Journey Map

A Guide for you and your GP