



Regional Dementia Care Pathway

Supporting Each Person's Individual Journey

MARCH 2018

Alternative Formats

This report can be made available in alternative formats: large print, computer disk, Braille, audio tape or translation for anyone not fluent in English. Please contact the Communications Office at the Health and Social Care Board www.hscboard.hscni.net.

Easy Read Format

Easy read versions of the contents of this document are available at www.hscboard.hscni.net/dementia.

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In line with Section 75 of the Northern Ireland Act 1998, Dementia Services will be provided and available to all irrespective of gender, ethnicity, political opinion, religious belief, disability, age, sexual orientation, dependant and marital status.

Dementia Services have a duty to each and every individual that they serve and must respect and protect their human rights. At the same time, Dementia Services also have a wide social duty to promote equality through the care they provide and in the way they provide care. This includes addressing the needs of those groups or sections of society who may be experiencing inequalities in health and well-being outcomes.

1.0 Foreword

On behalf of the Regional Dementia Care Pathway Collaborative, I am pleased to present to you this Dementia Care Pathway. This Pathway represents the out-workings of a number of recommendations from the Regional Dementia Strategy “Improving Dementia Services in NI” (2011) which are aimed at improving the services and support arrangements currently available for people with dementia, their families and their carers.

By 2051, it is estimated that there could be 60,000 people living with a dementia in NI. This will have a huge impact on the delivery of health and social care services. It is imperative therefore, that arrangements are put in place which provide an equitable, efficient and effective service that promotes independence and well-being and is both safe and affordable.

This ambitious Pathway will assist practitioners in the delivery of high quality, person-centred dementia care services from the point of initial engagement with service users to the end of life stage of the dementia journey. The model also acknowledges and includes provision for the needs of younger people with a dementia and persons with learning disability. This model of working represents a fully integrated approach based around primary care with services being delivered by a range of professionals and community support services.

This Pathway presents an exciting opportunity for the development of new roles within primary care and the need for a competent, highly skilled workforce will be pivotal to the success of its implementation.

As Chief Executive of the Health and Social Care Board and Public Health Agency, I am extremely grateful to all those individuals who assisted with this work and the many experts who offered advice and guidance along the way. In particular, I wish to thank members of Dementia NI who offered valuable advice, guidance and experience to the group.



Valerie Watts

Chief Executive, Health and Social Care Board/Public Health Agency

2.0 Acknowledgements

This Care Pathway has been jointly developed by people living with dementia, their carers and professionals involved in the commissioning and provision of care.

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3.0 Introduction

This Care Pathway has been jointly developed using the expertise of those working in dementia care and seeking the views of people living with dementia (Dementia NI) and the family and carers of people living with dementia through engagement in carer focus groups.

The Care Pathway takes account of the “Listening Well” report published by the Alzheimer’s Society (2009) which presented the views of people with dementia in the development of “Improving Dementia Services in Northern Ireland - a Regional Strategy” (2011). The Care Pathway is consistent with the principles contained in a Stepped Care Approach and NICE/SCIE Clinical Guideline 42: Supporting people with Dementia and their Carers in Health and Social Care (2011). The Care Pathway sets out the vision for high quality dementia services in Northern Ireland and allows those who provide dementia services to plan for future service development. The language in the Care Pathway is directed at the person with dementia but also applies to carers, families and service providers.

3.1 Why the Dementia Care Pathway was developed

- It is estimated that there are currently 20,000 people living with a dementia in Northern Ireland. It is projected that this number will increase; therefore dementia is recognised as a significant personal, social, health and economic issue both now and into the future.
- The Northern Ireland Dementia Strategy “Improving Dementia Services in Northern Ireland” published in 2011 set out recommendations on the delivery of dementia care. This pathway seeks to implement the recommendations contained within the Strategy.
- A Dementia Improvement Collaborative was established by the Health and Social Care Board in Spring 2015. This recognised the need to make improvements in dementia care, particularly in the area of addressing waiting times for memory assessments and follow-on reviews.
- A Health and Social Care Board Review of Dementia Services in Northern Ireland recognised the need to develop a standardised dementia care pathway which ensures high quality dementia care being delivered to all people with a dementia at the right time, in the right place and by the right people.
- A Dementia Innovation Lab, established in Summer 2015 to review the longer term implications of dementia for Northern Ireland, recommended a Regional Dementia Care Pathway to include all aspects of dementia care which values the involvement and individuality of people living with a dementia.

3.2 Who is this Dementia Care Pathway for?

This Care Pathway is for:

People with a Dementia or a Suspected Dementia

- of all ages
- who may also experience other health conditions
- who may also have a learning disability. People with learning disabilities, particularly those with Downs Syndrome, are at risk of developing dementia.
- who are at any stage of their journey with dementia
- regardless of where they live

Family and Carers

- Families and carers of people with a diagnosis of dementia or suspected dementia.

Staff

- Those who have an interest in or provide dementia care such as:
 - » Local Communities
 - » Health and Social Care Trusts
 - » Independent, Community and Voluntary organisations

3.3 Objectives of the Dementia Care Pathway

- Promote best practice principles across dementia services
- Promote healthy active ageing
- Improve public awareness and understanding of dementia
- Ensure timely and accurate diagnosis of dementia
- Improve the care and support offered to people living with a dementia and their family/carers.
- Maximise the independence and well-being of the person and their family/carers.
- Promote choice and inclusion of the person and their family/ carer in all decisions affecting them
- Provide information on the range of supports available to the person and their family/carers.
- Promote partnership working and integrated high quality care to ensure a positive experience for the person and their family/ carers

3.4 Values Governing the Dementia Care Pathway

There are a number of core values that underpin all dementia care which are outlined below.

Pathway Core Values

living well with Dementia



Enabling Experience



Early Intervention



Personalisation



Integrated



3.3 Description of the Core Values

Enabled Experience

People with a dementia and their carers have the opportunity to be informed of the process for memory assessment and the range of interventions and supports available across their dementia journey. They will also be involved in all decisions about their treatment and care and in giving feedback on their experience of the services received.

Early Intervention

Early Intervention including a timely and accurate diagnosis is important as it may give peace of mind and provide access to treatment and support which enable the person to live well for as long as possible and to plan for the future. Support offered will take account of the person's existing abilities and preferences together with family/carers, friends and community supports.

Personalisation

Recognition of each person's individual needs, choices and rights is essential. A personal well-being plan summarises the tailored supports that enable the person to live well with dementia. Regular review will ensure it is kept up to date and continues to meet any changing needs. There will be support for families/carers which will include the offer of a carer's assessment.

Integrated

It is important that people with dementia and their carers/family experience responsive and seamless care. All services will work together to ensure the right service is provided at the right time in the right place by the right person.

3.6 How the Dementia Care Pathway will be implemented

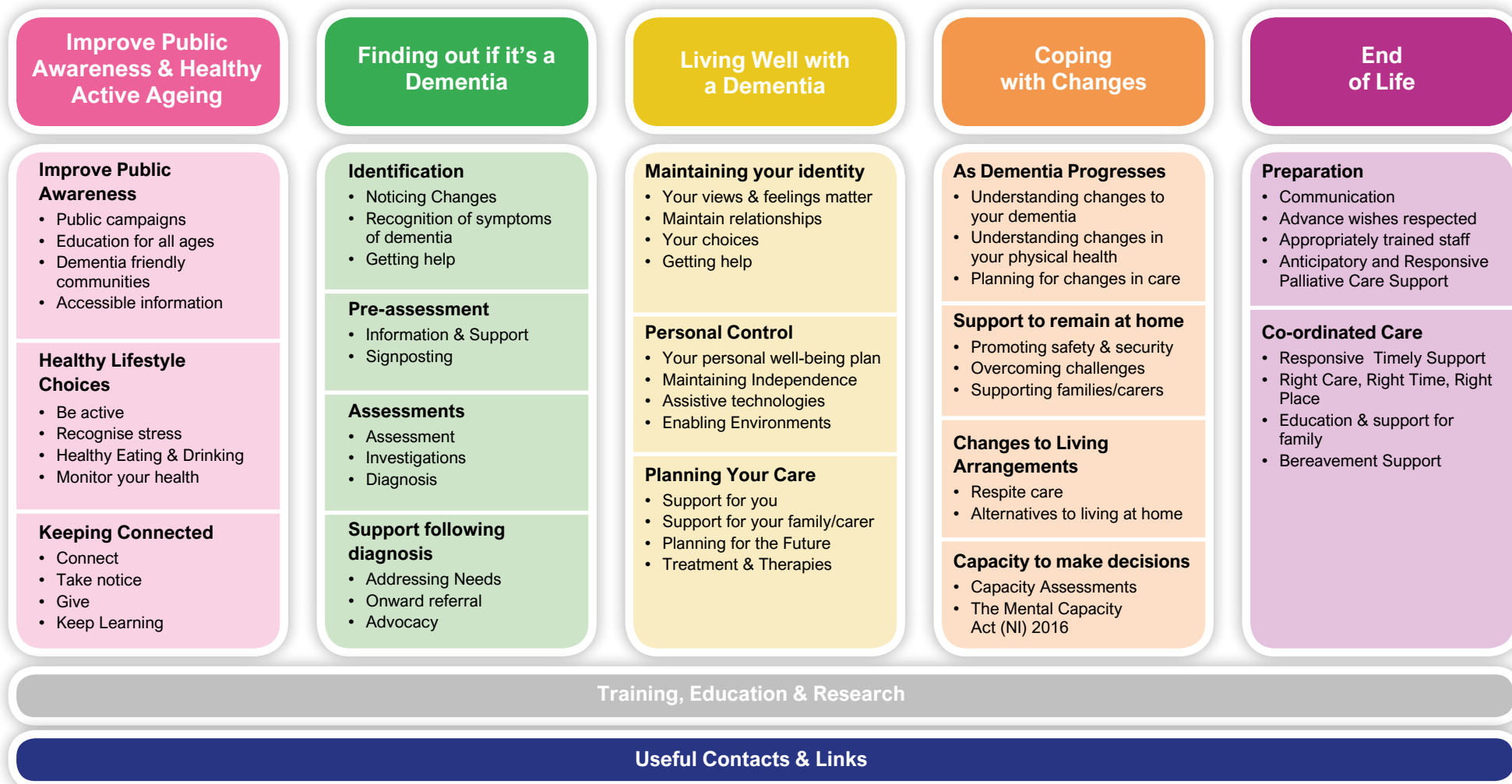
The Pathway will be implemented through the network of Integrated Care Partnerships.

- Integrated Care Partnerships (ICPs) are a new way of working for the health service in Northern Ireland to transform how care is delivered. The 17 ICPs across Northern Ireland are collaborative networks of care providers, bringing together healthcare professionals (including doctors, nurses, pharmacists, social workers, allied health professionals, ambulance services and hospital specialists); the voluntary and community sectors; local council representatives; and service users and carers, to design and co-ordinate local health and social care services and to work more closely together to keep people well in local communities.

3.7 How to use the Dementia Care Pathway

The pathway is a resource across the total dementia journey. It is intended that the user accesses information from the specific sections which are relevant to their stage of the journey.

3.8 The 5 Elements of the Dementia Care Pathway



4.0 Care Pathway

Working together across the voluntary and community sector, social care and health care means that people can receive early intervention, a timely diagnosis and access to the most appropriate post-diagnostic support.



4.0 Care Pathway

This section explains what is meant within each of the 5 Elements of the Dementia Care Pathway.

The 5 Elements are:

1. Improving Public Awareness and Healthy Active Ageing

2. Finding Out if it's a Dementia

3. Living Well with a Dementia

4. Coping with Changes

5. End of Life Care

Dementia does not have a linear pathway but like many other life limiting illnesses and long term conditions it does have a start and an end.

This pathway considers not just the needs of the person with dementia but also the carers and family, the community and the many services involved in caring and supporting.

The 5 Elements described in the Dementia Pathway embrace all the complexities across the dementia journey from the beginning to the end.

This pathway will guide you on the range of supports and services available throughout the journey.

4.1 Improving Public Awareness and Healthy Active Ageing

This section explains the key elements of improving public awareness about dementia, making healthy lifestyle choices and keeping connected.



4.2 Improving Public Awareness

Increasing awareness and education will help to address the stigma associated with dementia so that those living with dementia are valued and included in their communities and in all aspects of society.

- Improved public awareness will support the development of a dementia friendly community.
- An essential component of this is targeted age appropriate education:
 - » to raise awareness of the signs and symptoms of dementia
 - » to promote understanding of the needs and experiences of the person with dementia.
 - » to communicate effectively with the person with dementia.
- In a dementia friendly community everyone has an awareness of dementia, recognises dementia and responds in a supportive way to help the person with dementia remain an active and valued member of their community.
- There is access to timely information, advice, support and appropriate services through a range of organisations such as Alzheimer's Society, AGE NI, local Councils and Health and Social Care Trusts.

4.3 Healthy Active Ageing

There are a number of health conditions that may increase the risk of developing dementia. Everyone is at risk of developing heart disease, stroke, type 2 diabetes or kidney disease but often these diseases can be reduced. A healthy lifestyle may prevent or delay the onset of these conditions and dementia.



Healthy Lifestyle Choices

- Discover a physical activity you enjoy. Engage in physical activity that suits your level of mobility and fitness.
- Recognise stress and take appropriate action.
- Eat a healthy balanced diet.
- Maintain a healthy weight.
- Smoking and other drugs increase the risk of dementia. Stopping smoking can have real benefits. Drink alcohol in moderation.
- Be aware of changes in your body. Consult your GP if you have any concerns about your health. Keep blood pressure at a healthy level.
- Have regular health checks.

4.3 Healthy Active Ageing

Good mental health greatly improves your physical health and brain function.



Keeping Connected

- Keep connected with the people around you:
 - » Family
 - » Friends
 - » Colleagues and neighbours
 - » At home, work or in your local community.
- Be aware of the things around you, take time to enjoy life.
- Keeping socially active can prevent isolation. Seeing yourself linked to the wider community can be incredibly rewarding. Consider being a volunteer.
- Keep your brain active. Don't be afraid to try something new, rediscover an old hobby. Set a challenge you will enjoy. Learning new things will help your brain.

4.4 Finding out if it's a Dementia

This section explains the key elements of identification of changes to normal ageing and what is involved in the assessment process and what supports are available before and after a diagnosis. This includes supports that are available throughout your journey with a dementia.

Diagnostic Process at a Glance

If you have concerns about your memory, or experience other symptoms that impact on your daily living, or your family/GP notice such changes your GP will discuss your symptoms and other aspects of your health with you and carry out some initial tests to exclude other possible causes.

You will receive an explanation of the assessment process including the anticipated length of time it will take.

Your GP will follow the clinical pathway of assessment for a suspected dementia. Your GP will organise for other members of the team to carry out further assessments. These may include a more detailed memory assessment, an assessment of your functional abilities and an assessment of your social circumstances.

Your GP may refer you to a specialist if further assessment or inputs are required for your specific presenting symptoms. The specialist may be one or more of the following:

A Psychiatrist who is an expert in treating dementia and older people

A Psychiatrist who is an expert in treating dementia for people with a learning disability (refer to learning disability and dementia pathway)

A geriatrician who is an expert in treating physical illnesses in older people and dementia

A neurologist who is an expert in treating conditions that affect the brain and nervous system

A Memory Practitioner who is an expert in conducting memory assessments

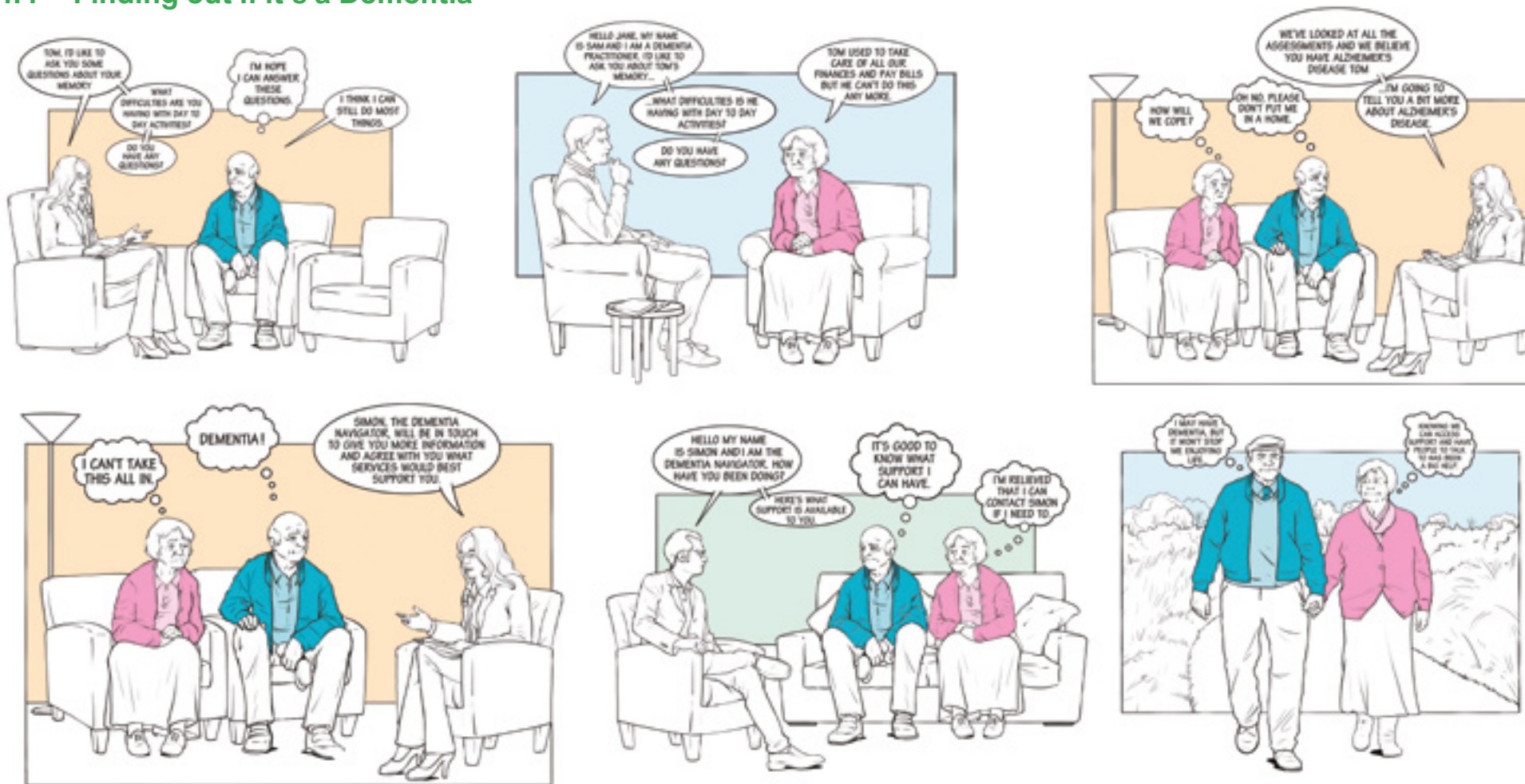
Once the necessary tests are completed your diagnosis will be shared with you if this is your wish or with a family member if more appropriate.

4.4 Finding out if it's a Dementia



By Dr Frances Duffy, Consultant Clinical Psychologist and Simon Hildich, Dementia Navigator, Northern Health and Social Care Trust. Thanks to Dementia NI for their helpful contribution to the design. © 2018 Northern Health & Social Care Trust Frances.Duffy@northerntrust.hscni.net

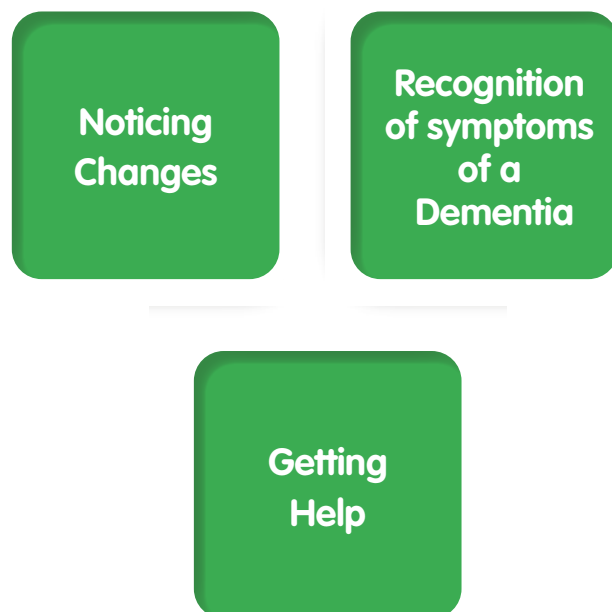
4.4 Finding out if it's a Dementia



By Dr Frances Duffy, Consultant Clinical Psychologist and Simon Hildich, Dementia Navigator, Northern Health and Social Care Trust. Thanks to Dementia NI for their helpful contribution to the design. © 2018 Northern Health & Social Care Trust Frances.Duffy@northerntrust.hscni.net

4.4 Finding out if it's a Dementia

A timely assessment is important to exclude other potentially reversible causes or changes in your thinking, memory, behaviour or day to day life. The assessment will take account of any pre-existing conditions you already have.



Identification

You or someone who knows you well may notice changes in your day-to-day living. Common symptoms include:

- » changes in your ability to think, learn, reason and remember
 - » confusion in familiar environments
 - » difficulty finding the right words
 - » increasing difficulty with routine tasks and activities
 - » changes in mood or behaviour
-
- If symptoms persist for six months or longer seek help.
 - Make an appointment with your GP to discuss your symptoms and concerns.
 - Your GP will carry out some initial tests to exclude any other medical causes for your symptoms. Depending on the outcome of the tests this will determine the most appropriate next steps.

4.4 Finding out if it's a Dementia

There is recognition that the time spent waiting for your assessment can be stressful. Therefore support is essential at this time.

Information
and
Support

Signposting

Pre-Assessment Support

- The information and support will help you decide if you want to have the assessment and prepare you and your family or carer for the assessment.
- If you consent to further investigations there will be a variety of support and information available whilst you are waiting for your formal assessment.
- The information and support will be available in a variety of formats.
- You will be given the contact details of an identified person and/or team so that you can contact them if you need more information or support.

4.4 Finding out if it's a Dementia

A diagnosis of dementia opens the door to information and supports that maximise your ability to live well.



Assessment

- Assessments will be completed, examples of these are:
 - » Physical examinations
 - » Memory/Cognitive tests
 - » Changes in your ability to complete activities of daily living
- Further investigations may be required.
- The outcome following your assessments may be that you do:
 - » not have a dementia
 - » have a dementia
 - » have mild cognitive impairment
 - » have a physical or mental health condition
- The outcome of the assessment will be discussed with you and your family, with your consent.
- Support will be available from a variety of sources to meet your individual requirements.
- A personal well-being plan will be agreed with you.

4.4 Finding out if it's a Dementia

Diagnostic Process at a Glance

If you are diagnosed with mild cognitive impairment:

- You will receive treatment for any underlying cause and a reassessment after treatment is completed.
- You will receive education and information on living a healthy lifestyle to maintain or improve your memory.
- You will be informed of changes, signs or symptoms to look out for.
- You will be informed of coping strategies you can use in your own home to maintain or improve your daily living skills.
- You can request a reassessment from your GP if you experience further changes or symptoms.
- A percentage of people with a diagnosis of MCI will go on to develop dementia

If you are diagnosed with a dementia:

- You will receive an explanation on what having dementia may mean for you:
 - » The type of dementia you have and what any plan to investigate further will entail.
 - » Details about symptoms and how the condition might develop.
 - » The offer of counselling.
 - » Information on appropriate treatments.
 - » A link to the dementia navigator who can advise you of support services in your area.
 - » Ensure you have written information about your condition.
- You and your family will be given time to ask any questions you might have.

4.4 Finding out if it's a Dementia

Early intervention after the diagnosis for both you and your family or carer will ensure that you feel supported and well informed.



Support Following Diagnosis

- You can access a Dementia Advocate who will have specific expertise and understanding of communication with people with dementia, the progression of dementia conditions and best practice in dementia care.
- Your personal well-being plan may include onward referral to a range of voluntary, community and health and social care services including specialist services.

4.4 Finding out if it's a Dementia

Learning Disabilities and Dementia

People with learning disabilities who develop dementia generally do so at a younger age.

A person with a significant learning disability will already have some differences in their thinking, reasoning, language or behaviour, and their ability to manage daily living. It is a change or deterioration in these, rather than a single assessment, that may suggest dementia. This means families, carers and others play an important part in helping to identify early signs of dementia and any concerns should be raised with the person's GP or learning disability team. The process for assessment and diagnosis for possible dementia is similar to that for the general population, however a learning disability does make the diagnosis more complicated and is therefore best made by a memory service specialising in the needs of adults with learning disabilities.

Down's Syndrome and Dementia

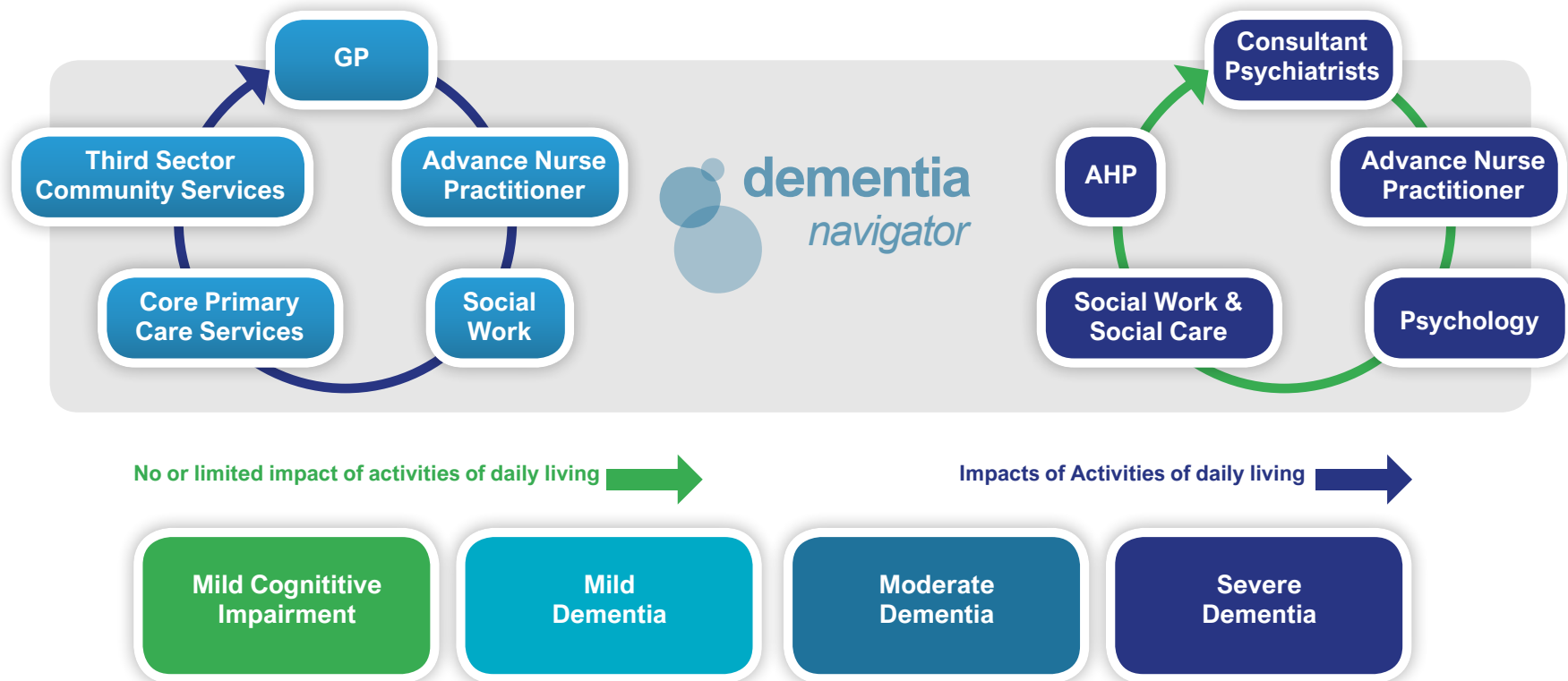
There is a greatly increased risk of developing dementia among people with Down's syndrome

It is recommended that every adult with Down's Syndrome is assessed at 30 years of age to provide a record or baseline with which future assessments can be compared. It may be necessary to repeat the assessment periodically before a diagnosis of dementia is made. As well as this baseline assessment an annual health check should be completed. This health check should lead to referral to a specialist if needed. Assessment and diagnosis of dementia is best done by a memory service specialising in the needs of adults with learning disabilities. A range of assessment tools have been developed specifically for people with Down's Syndrome or other learning disabilities.

4.4 Finding out if it's a Dementia

The Integrated Dementia Services Model

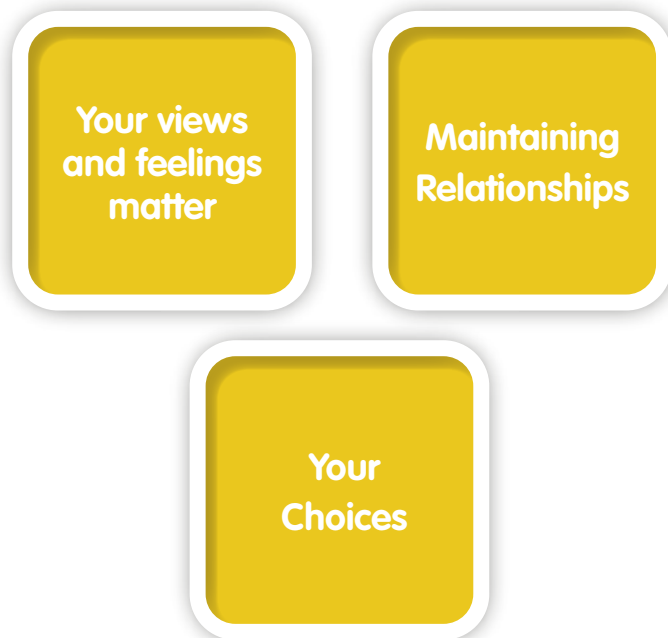
You will be able to access joined up health and social care support from a range of staff specialising in dementia care.



4.5 Living Well with a Dementia

Maintaining Your Identity

It is important to get to know you as an individual and what is important to you, including supporting you to maintain your own identity.



Together we will:

Look beyond the dementia by listening and understanding what matters to you and see the person not just the dementia.

- Respect the things that make you who you are, such as being a family member, friend, work colleague, a member of your local community.
- Respect that you will wish to remain in control of what happens in regard to your journey with dementia.
- Acknowledge that many aspects of your life before your diagnosis can still continue and that this is possible with the right supports.

4.5 Living Well with a Dementia

Personal Control

This means that you and your family/carer are able to maximise personal control and independence, choice and wellbeing.

Your
Personal
Well-being
Plan

Maintaining
Independence

- Your personal well-being plan will be developed in partnership with you.
- Your personal well-being plan summarises your individual needs, your individual choices and wishes, and, the supports available for day-to-day living.
- It is advisable to maintain your optimum level of independence in all areas of your life to enable you to have a meaningful, enjoyable and active life. This could be by being involved in local community groups, church activities, voluntary work, walking groups etc.

4.5 Living Well with a Dementia

Personal Control

This means that you are enabled, through the provision of aids and adaptations, to remain active and independent for as long as possible.



- There are a range of devices that can be installed in your home that can allow you to be independent for longer. They can help you to live your life the way you wish in a safer way.
- There are a number of changes that can be made to your home/living environment that can make life easier as the condition progresses.

4.5 Living Well with a Dementia

Planning Your Care

You and your family/carer will be treated as equal partners in all discussions and arrangements for any supports.

Support
for you

Support for
your
family/carer

- You will be assisted to maintain your independence by a range of supports that are appropriate to your needs. This may be emotional support, practical support or linking you to peer support groups.
- Community based programmes run by voluntary or faith groups can help you stay well, connected to your community and feel supported.
- There will be support for your family/carers. This will include the offer of a carer's assessment.

4.5 Living Well with a Dementia

Planning Your Care

It is important for you to plan for the future as your physical and cognitive needs will change as dementia progresses.



- An early assessment by an Occupational Therapist of your memory and how it affects your level of functioning can provide you with advice about memory intervention strategies. An Occupational Therapist can also advise on making changes to your environment to maximise your level of functioning both now and as your condition changes.
- It is advisable to make any necessary changes to your living environment early (eg downstairs bedroom and bathroom) as you may need these as the condition progresses. Any adaptations to your home can take a considerable time. An early assessment by an Occupational Therapist is needed to start this process.
- You will be assessed in regard to what therapies, medications and treatments might be appropriate for you. These will not cure the condition; rather it is about ways of compensating for difficulties or managing them better.
- Support will be available to look at advance care planning and future financial management including Power of Attorney or Making a Will.

4.6 Coping with Changes

Dementia is a progressive condition. Whilst research is ongoing, as yet there are no treatments that can change the fact that damage is ongoing in the brain. People with dementia are all individuals and dementia affects each person's life differently. Changes to your thinking, reasoning, communication, physical health and practical abilities such as eating and drinking can pose challenges and risks.

As Dementia Progresses

It is important to know that as dementia progresses it can cause changes in your judgement, feelings and behaviour that can be challenging for you and your family. Dementia can impact on your ability to make decisions, express your feelings and communicate your needs. Help will be available to understand the changes in your dementia and to be supported.



- It is important that you know who to contact when you need additional support to avoid crisis. This information will be contained within your personal well-being plan.
- If necessary there will be an assessment offered to determine what supports might help you to make decisions in your best interests.
- Training will be provided for you, your carers and family members to help understand how the changes associated with dementia can affect you and help everyone understand how best to support you
- Supports are available at these times including in the evenings and at weekends

4.6 Coping with Changes

As Dementia Progresses

Changes to your physical and mental health may cause you to be confused. Sometimes people may experience a delirium. These changes are usually temporary and will resolve once the underlying physical health condition is treated.

Understanding
Changes to
your Physical
Health

Planning for
Changes in
Care

- A range of supports are available to help you/your family. This will include supports at home, day care options, clinic attendance.
- A temporary admission to hospital may be necessary to manage an acute illness. However, there are Hospital at Home Services that may be appropriate and avoid the need for a hospital admission.
- A small number of people with dementia may experience behavioural changes which cause them to present with significant distress. This may require a period of assessment and treatment in a specialist dementia unit before returning to community living.

4.6 Coping with Changes

Support to Remain at Home

As your needs change you may require a reassessment of your circumstances to determine what supports you may require.



- Your personal well-being plan, where risks will be identified, will be completed in consultation with you and your family.
- Your plan will also outline your expressed future wishes and make provision for acting in your best interests if and when you no longer have the capacity to make decisions.
- Your plan will only be shared with those people who are responsible for helping you to maintain your safety and well-being.

4.6 Coping with Changes

Changes to Living Arrangements

Dementia makes it likely that you will require more practical help as time goes on and you may potentially need more help including where you live.

Respite
Care

Alternatives
to Living at
Home

- Support can be provided with daily living tasks such as personal care.
- Respite Care for example in a care home appropriate to your needs may give you an opportunity to recover after an acute illness or to give your carer a rest.
- There may be alternative supported housing options appropriate to your needs:
 - » Supported Housing
 - » Residential Home
 - » Nursing Home

4.6 Coping with Changes

Capacity to make decisions

You may reach a stage where dementia affects your ability to make specific decisions

Capacity
Assessments

Mental
Capacity Act
(NI) 2016

- Capacity assessment is decision and time-specific for example you may have capacity to make decisions about your living arrangements but you may not have capacity to make decisions about you finances.
- As far as possible your expressed wishes will be considered and all advance decisions can be reviewed and revised in accordance with your needs, preferences and safety requirements.
- Under the Mental Capacity Act (NI) 2016 you may require a capacity assessment to make specific decisions for example in regard to your finances or future care arrangements.

4.7 End-of-Life

Like all citizens, people living with dementia should have the opportunity to prepare for their own death whether it is from dementia or another illness. There is access to a wide range of supports including palliative care services. People with dementia and their carers/families will feel supported through this stage.



Preparation

As with some other conditions there are indicators that suggest when a person with dementia may be in their last year of life.

- Important conversations should take place as early as possible in order to plan the supports needed to have a good death in the right place
- If advance plans or wishes have been expressed, these are respected as far as possible.
- Staff and carers are appropriately trained in the specific needs of people at the end of life
- The information, care and support you receive will help you feel safe, comfortable and dignified.

4.7 End-of-Life

Co-ordinated Care

You will be respected as a whole person, not treated as a condition. You can remain in control as much as possible. This is recognised as a key goal in your care.



- A person with dementia at this stage will have access to the full range of health and social care services including palliative care services as appropriate to their care needs.
- Palliative Care includes management of complex symptoms such as pain. Palliative professionals will use appropriate assessment tools considering the needs of the person with dementia.
- Everyone who cares for and supports you and your carer work together. The care will be delivered in the most appropriate place for you.
- Your carers and family will be supported at this time.
- Bereavement support will be offered to your carers/family.

Overview of Dementia Care Pathway

Element	Focus	Lead Agencies	
1	Improving Public Awareness and Healthy Active Ageing	Living well and Prevention/Delayed Onset Dementia Friendly Communities	Public Health Agency Primary Care Teams Community/Third Sector Local councils
2	Finding Out if its Dementia	Identification Pre-assessment support Assessment Support following diagnosis	Primary Care Teams for Dementia Secondary Care Dementia Specialists Dementia Navigators
3	Living Well with Dementia	Maintaining Identity Personal Control Planning Care	Primary Care Teams for Dementia Dementia Navigators Community/Third Sector
4	Coping with Changes	As Dementia Progresses Support to remain at home Changes to living arrangements Capacity to make decisions	Secondary Care Dementia Specialists
5	End of Life Care	Preparation Co-ordinated Care	Secondary Care Dementia Specialists Palliative Care Services

Dementia is a progressive condition. People progress from mild to moderate dementia and, eventually to more severe dementia over a period of years. There are a range of services to support you and your carer. Working with you we will ensure the right supports are available at the right time in the right place.

5.0 Useful Contacts & Links

This section details a range of useful contacts and their links across the 5 Elements that will provide you and your family/carer with further information.

This is not an exhaustive list as services will continue to develop.

The Dementia Navigator or your key worker will be able to advise you of any new services and those in your local area and how to access them.

The contacts listed are mainly in relation to dementia-specific supports.

Improving Public Awareness and Healthy Active Ageing

- Age NI
www.ageuk.org.uk/northern-ireland
- Dementia Friendly Communities
www.alz.co.uk/dementia-friendly-communities/northern-ireland
- Local Government Councils
www.gov.uk/find-local-council
- Public Health Agency Information
www.public.health.hscni.net

Finding out if its a Dementia

<p>Booklets Are you worried about Dementia? The early stages of Dementia</p>	<p>www.pha.site/dementiadocs</p>
<p>Local Community Care Services Covers a range of services including; Dietetics, Nursing, Occupational Therapy, Physiotherapy, Podiatry, Social Work, Speech & Language Provision of Assessment for Care Packages at Home or Residential and Nursing Homes</p>	<p>www.belfasttrust.hscni.net www.northerntrust.hscni.net www.setrust.hscni.net www.southerntrust.hscni.net www.westerntrust.hscni.net</p>
<p>Local Primary Care Team</p> <ul style="list-style-type: none"> - Advanced Nurse Practitioner - GP - Social Worker - Occupational therapist 	<p>Contact your local GP Practice</p>
<p>Local Trusts:</p> <ul style="list-style-type: none"> - Dementia Navigator - Memory Assessment Services 	<p>www.belfasttrust.hscni.net/services/Dementia www.northerntrust.hscni.net/services/1807.htm www.setrust.hscni.net/services/2302.htm www.southerntrust.hscni.net/services/1709.htm www.westerntrust.hscni.net/services/2651.htm</p>

Living Well with a Dementia

<p>Booklets</p> <ul style="list-style-type: none"> Eating, drinking and swallowing: A guide for carers of people living with a dementia Dementia and care of natural teeth and dentures Talking about risk and dementia Dementia and moving to a care home Sexuality, relationships and dementia Dementia and sight loss Planning ahead with dementia 10 common signs of dementia Communicating effectively with a person living with a dementia 	<p>www.pha.site/dementiadocs</p>
<p>Advance Care Planning</p>	<p>www.nhs.uk/conditions/dementia-guide/pages/dementia-diagnosis-plan.aspx</p> <p>Online tools with information on a wide range of assistive technologies are available at:</p> <ul style="list-style-type: none"> www.atdementia.org.uk www.unforgettable.org.uk www.nrshealthcare.org.uk
<p>Creative Art Therapies</p>	<p>www.arts4dementia.org.uk</p>
<p>Dementia Cafes</p>	<p>http://www.alzheimercafe.co.uk</p>
<p>Dementia Information Northern Ireland</p>	<p>www.nidirect.gov.uk/dementia</p>
<p>Dementia NI</p>	<p>www.dementiani.org</p>
<p>Dementia Services Development Centre</p>	<p>www.dementia.stir.ac.uk</p>
<p>NI Alzheimers Society</p>	<p>www.alzheimers.org.uk/northernireland</p>
<p>This is Me Tool</p>	<p>www.alzheimers.org.uk/thisisme</p>

Coping with Changes

Butterfly Scheme	www.butterflyscheme.org.uk
John's Campaign	www.johnscampaign.org.uk
Local Trust Dementia Services	www.belfasttrust.hscni.net/services/Dementia www.northerntrust.hscni.net/services/1807.htm www.setrust.hscni.net/services/2302.htm www.southerntrust.hscni.net/services/1709.htm www.westerntrust.hscni.net/services/2651.htm
Carers NI Factsheet – When Caring Ends or Changes	www.carersuk.org/help-and-advice/practical-support/when-caring-ends
Power of Attorney	www.justice-ni.gov.uk/articles/information-enduring-powers-attorney-epa
Controllership	www.justice-ni.gov.uk/articles/how-apply-become-controller

End-of-Life

All Ireland Institute of Hospice & Palliative Care (AIHPC)	www.aiihpc.org/palliative-hub
Dying Matters	www.dyingmatters.org
Local Community Care Services	www.belfasttrust.hscni.net www.northerntrust.hscni.net www.setrust.hscni.net www.southerntrust.hscni.net www.westerntrust.hscni.net
Local Primary Care Team - District Nurse - GP	Contact your local GP Practice
Local Trusts Palliative Care Services	www.belfasttrust.hscni.net www.northerntrust.hscni.net www.setrust.hscni.net www.southerntrust.hscni.net www.westerntrust.hscni.net
Marie Curie - Home Nursing Services - Hospice Care Services	www.mariecurie.org.uk
NI Hospice	www.nihospice.org

6.0 Training, Education & Research

Training and education is needed to ensure all those who care for and support people with dementia have the right knowledge and skills to do their job well. Research empowers people with a dementia and their carers and enables them to help improve diagnosis, treatment and care.



- The Voluntary, Community, Independent Sectors and Health and Social Care Trusts offer training to carers. The Dementia Navigator or key worker will connect carers to training in their local area.
- The Multidisciplinary Learning Networks allow staff performing different roles in dementia care and support to learn and develop together.
- The Dementia Learning and Development Framework sets out the knowledge and skills that staff across the public and private sectors will require in order to improve care for people with dementia www.hscboard.hscni.net/dementia.
- Further information on how to join dementia research is available at: www.joindementiaresearch.nihr.ac.uk.

7.0 Supporting Resources

This section provides a list of resources used to support the development of the pathway.

Improving Public Awareness and Healthy Active Ageing

Alzheimers Australia, Guiding Person Centred Dementia Care in the Community

Alzheimers Society (2013) Building Dementia Friendly Communities, a priority for everyone

World Health Organisation and Dementia Disease International (2012) Dementia: A Public Health Priority, World Health Organisation, Geneva

Finding out if it's a Dementia

Barrett Dr E, Shires Health Care - Hardwick CCG, Burns Professor A, NHS England (2014) Dementia Revealed, What Primary Care Needs to Know: A primer for General Practice

Burns A et al (2015) Dementia Diagnosis and Management: a pragmatic resource for general practitioners, NHS England

Burns A, Wilkinson A, Peachy S (2014) Best Practice in Memory Services: Learning from across England. NHS England and NHS IQ

Dementia Together NI (2016) Are you Worried about Dementia? Health and Social Care Board, Public Health Agency, Belfast

Dodd E et al (2014) Research Article: An evaluation of primary care led dementia diagnostic services in Bristol, England

Goodwin, N, Curry N, et al, (2010) The Kings Fund Research Paper - Managing people with long term conditions

Hawkins J (2015) Models of Dementia Assessment and Diagnosis: Indicative Cost Review, NHS England

Morris Dr P (2010) Dementia: Key Points in the Diagnosis of Dementia in Primary Care, NHS Borders, Scotland

The All Party Parliamentary Group on Dementia (2012) Unlocking Diagnosis The Key to Improving the Lives of People with Dementia, the Stationery Office, London

Workman, B, Dickson, F, Green, S (2010) Early Dementia, optimal management in general practice, Australian Family Physician Vol 39, No 10, Australia

Living Well with Dementia

Andrews, J and House A (2009) 10 Helpful Hints for Carers - Practical Solutions for Carers living with people with Dementia, Dementia Services Development Centre, Stirling

Brooker, D Latham I (2015) Person-centred dementia care: Making services better with the VIPS framework. Jessica Kingsley Publishers, London

Dementia Services Development Centre (2010) 10 Helpful Hints for Dementia Design at Home, Practical design solutions for carers living at home with someone who has dementia, Dementia Services Development Centre, Stirling

Dementia Together NI (2016) The Early Stages of Dementia, Health and Social Care Board, Public Health Agency, Belfast

Gibson F (2011) Reminiscence and Life story work: A Practical Guide Jessica Kingsley Publishers: London

McGrath MP, Passmore AP, (2009) The Home – Based Memory Rehabilitation Programme for Persons with Mild Alzheimers Disease and other Dementias, Belfast

Coping with Changes

Dementia Services Development Centre (2015) 10 Helpful Hints for When a Person with Dementia has to go to Hospital, Dementia Services Development Centre, Stirling

Duffy, F (2016) Look at all of me; A Clear model for dementia care, The Journal of Dementia Care, 22(3) 27-30

O'Shea, E, Manning, E, Timmons, Dr S, Ross E and McErlean S (2015) The Northern Ireland Audit of Dementia Care in Acute Hospitals. HSCB/PHA, Belfast

RCN/DOH (2013) Dementia: Commitment to the care of people with dementia in hospital settings

RCN/DOH (2010) Improving Quality of Care for People with Dementia in general hospitals

End-of-Life

DHSSPS(2010) Living Matters: Dying Matters – A Palliative and End of Life Strategy for Adults in Northern Ireland, Belfast

DHSSPS(2009) NI Health and Social Care Strategy for Bereavement Care, Belfast

NHS England, The National Council for Palliative Care and National Voices (2015) Every Moment Counts, England

Across the 5 Elements

Alzheimer's Scotland (2012), Delivering Integrated Dementia Care: The 8 Pillars of Community Support

Australian Health Ministers Advisory Council (2015) National Framework for Action on Dementia 2015-19, Australia

Dementia Partnerships (2012) Transforming Models of care for people living with dementia

Department of Health (DOH) (2001) National Service Framework for Older People: Modern Standards and Service Models, Stationery Office, London

DHSSPS (2011) Improving Dementia Services in Northern Ireland: A Regional Strategy, DHSSPS, Belfast

DHSSPS (2011) Service Framework for Mental Health and Well-being DHSSPS, Belfast

Joseph Rowntree Foundation : Supporting Derek : a practice development guide to support staff working with people who have a learning disability and dementia

Ministry Of Health, (2013) New Zealand Framework for Dementia Care

Naidoo M, Bullock R (2001) An Integrated Care Pathway for Dementia, Kingshill Research Centre, Swindon, UK

Stoker K, Mackie S, Green R, Dementia ICP development Group (2011) NHS Forth Valley Integrated Care pathway for Dementia, Scotland

The Dementia Engagement and Empowerment Project (DEEP) (2014) Dementia words matter: Guidelines on language about dementia, Centre for Ageing Research and Development in Ireland, Ireland

8.0 Clinical and Professional Practice Guidelines

This section outlines the professional and clinical guidelines that should be adhered to by dementia practitioners.

British Psychological Society (BPS) (2014). A Guide to Psychosocial Interventions in the Early Stages of Dementia Care.

British Psychological Society (BPS) (2014). Clinical Psychology in the Early Stage Dementia Care Pathway.

British Psychological Society (BPS) (2016). Psychological Dimensions of Dementia: Putting the Person at the Centre of Care,

British Psychological Society and Royal College of Psychiatrists (2015) Dementia and People with Intellectual Difficulties: Guidance on the Assessment, Diagnosis, Interventions and Support of People with Intellectual Difficulties who Develop Dementia, Leicester

DHSSPS (2015) Adult Safeguarding Prevention and Protection in Partnership Policy, Department of Health, Social Services and Public Safety and Department of Justice, Belfast

DHSSPS (2003) Good Practice in Consent. Consent for examination, treatment or care: A handbook for the HPSS. Department of Health, Social Services and Public Safety, Belfast

DHSSPS (2013) Guidelines for palliative and end of life care in nursing homes and residential homes, GAIN guidelines, DHSSPS, Belfast

Guidance for Health and Social Care Professionals: Caring for People in the Final Days and Hours of Life, DHSSPS, June 2016

Hodge, S, and Orrell, M, (eds) (2010) (2E) Memory Services National Accreditation Programme (MSNAP): Standards for Memory Services, Assessment and Diagnosis, Royal College of Psychiatrists, Doncaster

NICE Clinical Guideline NG31 (2016) Care of dying adults in the last days of life

NICE Quality Standard 30 (2013) Supporting People to Live Well with Dementia, NICE, Manchester

NIPEC (2011) Palliative and End of Life care Competency Assessment Tool, HSCB, Belfast

National Institute for Clinical Excellence (NICE) (2011) A NICE-SCIE Guideline on supporting people with dementia and their carers in health and social care. National Clinical Practice Guideline Number 42, HMSO, London

National Institute For Health and Clinical Excellence (NICE) (2010) Clinical Guideline 103, Delirium: diagnosis, prevention and management, HMSO, London

Reinhard G and Colleagues (2014) A Guide to Psychosocial Interventions in Early Stages of Dementia, The British Psychological Society, Leicester

Reinhard G and Colleagues, The British Psychological Society (2014) Clinical Psychology in the Early Stage Dementia Care Pathway, Leicester

Royal College of General Practitioners (2013) Guidance And Competencies for the Provision of Services using General Practitioners with Special Interest (GPwSI) in Dementia,

Sedgewick, R and Belfast Health and Social Care Trust (2014) Communicating Effectively with a Person Living with a Dementia. Public Health Agency and Dementia Together NI, Belfast

Taggart, W and Southern Health and Social Care Trust (2014) Eating, Drinking and Swallowing: A guide for a person living with a Dementia. Public Health Agency and Dementia Together NI

9.0 Glossary of Terms

Advance Care Planning (ACP)

Advance Care planning is a process of discussing and/or formally documenting wishes for your future care. It enables health and care professionals to understand how you want to be cared for if you become too ill to make decisions or speak for yourself.

Advocacy

Advocacy means ensuring that a person's views are heard so that their needs are met by helping the person get the care and supports they need. The person who offers this support is referred to as an advocate. An advocate is independent of any organisation

Allied Health Professionals (AHPs)

A diverse group of clinicians which includes dietetics, occupational therapy, physiotherapy, podiatry and speech and language therapy. Practical interventions from AHPs are often significant in enabling people to recover movement and mobility, improve nutritional status, develop communication and everyday living skills, thus allowing them to sustain and enjoy quality of life even when faced with life-limiting conditions.

Assistive Technology

Assistive technology can be defined as “any device or system that allows an individual to perform a task that they would otherwise be unable to do, or increases the ease and safety with which the task can be performed.” This includes a wide range of devices from simple ‘low tech’ items such as calendar clocks to more ‘high tech’ items such as automatic lighting and telecare sensors.

Capacity Assessment

The ability to make decisions independently is often referred to as having capacity. Injury, illness or disability can limit a person's ability to understand complex choices and to make decisions. Where any doubt exists as to a person's capacity to take a decision, an appropriate person can assess the capacity of the person.

Cognition/Cognitive Tests

Cognition refers to conscious mental activities and includes thinking, reasoning, understanding, learning and remembering. Cognitive Tests are tests of mental abilities used to help diagnose dementia.

Complicated Mild Cognitive Impairment and Atypical Dementias

For the purposes of this pathway the use of the terms complicated and atypical in relation to mild cognitive impairment and dementia refers to when the presentation of the person's symptoms are deemed to be more unusual and not typical to the memory team in terms of making an assessment and diagnosis. These presentations require more specialist interventions.

Delirium

Delirium is a medical condition that results in confusion and other disruptions in thinking and behaviour, including changes in perception, attention, mood and activity level. Individuals living with dementia are highly susceptible to delirium.

Dementia

Dementia is an umbrella term. It describes the symptoms that occur when the brain is affected by certain diseases or conditions. Symptoms of dementia include loss of memory, confusion and problems with speech and understanding. There are many different types of dementia and are often named according to the condition that has caused the dementia.

Dementia Navigator

These are health and social care staff within each Health and Social Care Trust whose role it is to provide information and support to those affected by dementia.

Dementia Primary Care Team

This consists of the team based in your local GP practice who have developed an interest and expertise in the diagnosis and management of non-complicated Mild cognitive impairment and non-complicated dementias. The team will consist of health and social care professionals and will usually include the GP, Advanced Nurse Practitioner, Social worker and Occupational therapist. The team maintains close links with the Dementia Specialist Team in their area to receive consultation advice on the management of their patient's treatment and care.

Dementia Specialist Team

This is a team who have an expertise in assessing and diagnosing all dementias but with a focus on managing those patients who present with the more complicated and atypical dementias. The team will consist of health and social care professionals and will usually include psychiatrists, nurses, psychologists, occupational therapists,

speech and language therapists and social workers. The team maintains close links with the Dementia Primary Care Teams in their area to offer consultation advice on the management of their patient's treatment and care.

Dementia Support Hub

A Dementia Support Hub provides a one stop access of support for people with dementia and their carers. The Dementia Navigator or key worker can explain the services available in your local hub.

Early onset dementia

A dementia where symptoms commence before the person's 65th birthday and is also often described as young onset dementia. Those diagnosed with early onset dementia often have different needs and therefore require some different supports.

Enduring Power of Attorney (EPA)

You can give someone the legal power to make decisions about your financial or health affairs should you lose the ability to make decisions. They can act for you now, if you wish, and in the future should you become unable to make

decisions for yourself. If you have not made an EPA and you become unable to manage your affairs it may be necessary to appoint a controller to manage them on your behalf. This can be done through the Office of Care and Protection. If managing your financial affairs consists of managing your income from benefits it may be done through appointeeship.

Key Worker

A main contact person who with your consent and agreement takes a key role in co-ordinating your care and promoting continuity, ensuring you know who to contact for information and advice.

Mild Cognitive Impairment (MCI)

Mild Cognitive Impairment(MCI) is a condition where a person has problems with memory or thinking which are more than would normally be expected for a healthy person of their age. MCI is not a type of dementia. Research studies indicate 10-15% of people with MCI go on to develop dementia so it is beneficial for a person diagnosed with MCI to seek support and make necessary lifestyle changes.

Non complicated Mild Cognitive Impairment and Dementias

For the purposes of this pathway the use of the term non-complicated in relation to mild cognitive impairment and dementia refers to when the presentation of the person's symptoms are deemed to be more apparent and straightforward to the primary care memory team in terms of making an assessment and diagnosis. It does not imply there is any less impact from the condition for the person/their family.

Palliative Care Services

Specialist level palliative care is delivered by a multidisciplinary team (MDT) of staff with the qualifications, expertise and experience in offering care for this group of people, to support them to live as well as possible during their illness ensuring their comfort and dignity are maintained as they come to the end of their lives. Input from specialist level palliative care professionals to the care of a person is based on the needs of the person and not the illness they have.

Personal Well-being Plan

A plan to help record information to manage your condition. It keeps information about you and your care in one place and is helpful to the health and social care professionals involved in your care to ensure proper co-ordination of your care.

Respite Care

Respite care involves short term or temporary care of a few hours or weeks. Respite care is designed to provide relief, or respite, to the regular caregiver, usually a family member

Specialist Dementia Care Unit

The specialist dementia care unit can provide additional specialist residential support for people with changing behaviours and psychological needs.

Supported Living

Supported living combines housing with support services. They aim to help people to live as independently as possible. The accommodation can have adaptations and the person can receive community or social services supports such as assistance with personal care

10.0 I would like more information

SERVICE	WHAT THEY DO	HOW TO CONTACT
To be completed by you or your family/carer	To be completed by Dementia Navigator/Key Worker	To be completed by Dementia Navigator/Key Worker

11.0 This is Me

The “This is Me” Tool allows you or your carer to provide personal information about you. This can help those caring for you to know you as a person. It can also help ensure that your needs and your preferences are known by those who are caring and supporting you.

This tool is available for download at www.alzheimers.org.uk/thisisme

In partnership with



Royal College
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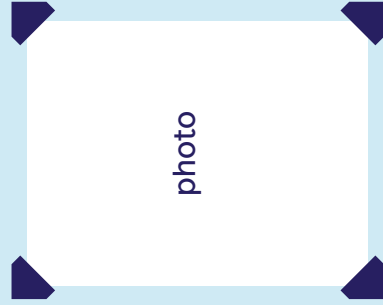


This is me

This leaflet will help
you support me in
an unfamiliar place.

My full name is _____

- Please place a photograph of yourself in the space provided.
- Turn to the back page of this form for guidance notes to help you complete **This is me**, including examples of the kind of information to include.
- Keep the completed form in a suitable place so that all care staff can see it and refer to it easily.



Someone who has dementia, delirium or other communication difficulties, can find changes, such as moving to an unfamiliar place or meeting new people who contribute to their care, unsettling or distressing. **This is me** provides information about the person at the time the document is completed. It can help health and social care professionals to build a better understanding of who the person really is.

This is me should be completed by the individual(s) who know the person best and, wherever possible, with the person involved. It should be updated as necessary. It is not a medical document.

Refer to the notes on the back page to help fill in the categories below.

My full name

Name I like to be called

Where I live (list your area, not your full address)

Carer/the person who knows me best

I would like you to know

My background, family and friends (home, pets and any treasured possessions)

Current and past interests, jobs and places I have lived and visited

The following routines are important to me

Things that may worry or upset me

What makes me feel better if I am anxious or upset

My hearing and eyesight

How we can communicate

My mobility

My sleep

My personal care

How I take my medication

My eating and drinking

Other notes about me

Date completed

By whom

Relationship to person

I agree that the information in this leaflet may be shared with health and social care professionals.

Guidance notes to help you to complete This is me

Name I like to be called: Enter your full name on the front and the name you like to be called inside.

Where I live: The area (not the address) where you live and how long you have lived there.

Carer/the person who knows me best: This may be a spouse, relative, friend or carer.

I would like you to know: Include anything you feel is important and will help staff to get to know and care for you, eg I have dementia, I have never been in hospital before, I prefer female carers, I am left-handed, I am allergic to..., other languages I can speak.

My background, family and friends (home, pets and any treasured possessions): Include place of birth, education, marital status, children, grandchildren, friends and pets. Add religious or cultural considerations.

Current and past interests, jobs and places I have lived and visited: Include career history, voluntary experience, clubs and memberships, hobbies, sports or cultural interests, favourite or significant places.

The following routines are important to me: What time do you usually get up/go to bed? Do you have a regular nap or enjoy a snack or walk at a particular time in the day? Do you have a hot drink before bed, carry out personal care activities in a particular order or like to watch the evening news? What time do you prefer to have breakfast, lunch, evening meal?

Things that may worry or upset me: Include anything you may find troubling, eg family concerns, being apart from a loved one, or physical needs such as being in pain, constipated, thirsty or hungry. List environmental factors that may also make you feel anxious, eg open doors, loud voices or the dark.

What makes me feel better if I am anxious or upset: Include things that may help if you become unhappy or distressed, eg comforting words, music or TV. Do you like company and someone sitting and talking with you or do you prefer quiet time alone?

My hearing and eyesight: Can you hear well or do you need a hearing aid? How is it best to approach you? Is the use of touch appropriate? Do you wear glasses or need any other vision aids?

How we can communicate: How do you usually communicate, eg verbally, using gestures, pointing or a mixture of both? Is the use of touch appropriate? Can you read and write and does writing things down help? How do you indicate pain, discomfort, thirst or hunger? Include anything that may help staff identify your needs.

My mobility: Are you fully mobile or do you need help? Do you need a walking aid? Is your mobility affected by surfaces? Can you use stairs? Can you stand unaided from a sitting position? Do you need handrails? Do you need a special chair or cushion, or do your feet need raising to make you comfortable? What physical activity do you take?

My sleep: Include usual sleep patterns and bedtime routine. Do you like a light left on or do you find it difficult to find the toilet at night? Do you have a favoured position in bed, special mattress or pillow?

My personal care: List your usual practices, preferences and level of assistance required in the bath, shower or other. Do you prefer a male or female carer? Do you have preferences for brands of soaps, cosmetics, toiletries, continence aids, shaving or teeth cleaning products and dentures? Do you have particular care or styling requirements for your hair?

How I take my medication: Do you need help to take medication? Do you prefer to take liquid medication?

My eating and drinking: Do you prefer tea or coffee? Do you need help to eat or drink? Can you use cutlery or do you prefer finger foods? Do you need adapted aids such as cutlery or crockery to eat and drink? Does food need to be cut into pieces? Do you wear dentures to eat or do you have swallowing difficulties? What texture of food is required to help – soft or liquidised? Do you require thickened fluids? List any special dietary requirements or preferences including being vegetarian, and religious or cultural needs. Include information about your appetite and whether you need help to choose food from a menu.

Other notes about me: Include additional details about you that are not listed above and help to show who you are, eg favourite TV programmes or places, favourite meals or food you dislike, significant events in your past, expectations and aspirations you have.

Indicate any advance plans that you have made, including the person you have appointed as your attorney, and where health and social care professionals can find this information.

Download this form or order copies online at [alzheimers.org.uk/thisisme](https://www.alzheimers.org.uk/thisisme) or call 0300 303 5933.

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Call the National Dementia Helpline on 0300 222 1122 or visit [alzheimers.org.uk](https://www.alzheimers.org.uk)

Notes

Notes

Living Well
with Dementia

Coping with
Changes

End of
Life

Finding out
if it's a
Dementia

Improving Public
Awareness and
Healthy Active
Ageing



Supporting Each Person's Individual Journey

www.hscboard.hscni.net/dementia