



Living Well with Dementia

in Stoke-on-Trent - Joint Dementia Strategy 2020-24

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Stoke-on-Trent
Clinical Commissioning Group



City of
Stoke-on-Trent

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Foreword

In Stoke-on-Trent, we have been working with our partners to improve services and support for people living with dementia and their carers. As a result there has been great improvement in our diagnosis rates and the services available to support people with dementia and their carers.

There is still much to be done. The number of people affected by dementia is increasing significantly, yet the condition still carries a great deal of stigma and fear. This can often prevent people from seeking the support they need and lead to them becoming disconnected from their communities. With access to the right support, treatment and care people can live well with dementia. This is the message that we want to spread loud and clear throughout the city.

We want Stoke-on-Trent to become a Dementia Friendly City. Achieving this means working together as a city. People with dementia and their carers must have a voice; be actively involved in shaping and developing services; and feel truly part of their communities.

We will continue to work closely with our partners through the Stoke-on-Trent and North Staffordshire Dementia Steering Group. We thank all members of this multi-agency group for their on-going commitment, support and contributions. The Dementia Strategy for Stoke-on-Trent is jointly presented by Stoke-on-Trent City Council and Stoke-on-Trent's Clinical Commissioning Group. The strategy sets out our shared vision and aspirations for improving dementia services within the city over the next four years.

Consultation during summer 2019 has re-affirmed the vision and priorities set out in the original strategy for 2015-19. We will continue to focus on these. Thank you to everyone who shared their views during the consultation and helped us to refresh our strategy for 2020-2024.

Working together with our partners, we are committed to making this strategy a reality and providing support to help people affected by dementia in Stoke-on-Trent to live well.

Introduction

This dementia strategy is jointly presented by Stoke-on-Trent City Council and Stoke-on-Trent Clinical Commissioning Group to reflect the local perspective within the wider regional and national context. Almost 885,000 older people are estimated to be living with dementia in the United Kingdom in 2019.¹ The term 'Dementia' is used to describe a collection of symptoms, including a decline in memory, reasoning and communication skills, and a gradual loss of skills needed to carry out daily activities. Dementia mainly affects older people, and after the age of 65, the likelihood of developing dementia roughly doubles every five years.

Dementia is the leading cause of death in the UK. ¹

As age is the greatest risk factor for dementia and life expectancy is rising, dementia is a growing challenge. The number of people with dementia is forecast to increase to over one million by 2024, and 1.6 million by 2040.¹ The prevalence rate of dementia among older people in the UK is estimated to be 7.1% in 2019. ² The higher life expectancy of women is translated into higher prevalence of dementia in older age groups.

This year one person will develop dementia every three minutes, according to the Alzheimer's Society website.

The most common type of dementia is Alzheimer's disease. Vascular dementia is the second most common form of dementia. A number of modifiable risk factors have been identified as possible precursors to dementia including high blood pressure, smoking, excessive alcohol consumption and obesity.

It is difficult to determine how many people with dementia will need care and support. Personal circumstance and individual disease trajectory will have a bearing on specific requirements. However dementia presents a major and serious challenge to health and social care in terms of: the increasing numbers of people affected by dementia; and the rising cost of providing a range of good quality services to enable people with dementia and their carers to live well. Recent evidence suggests that there are around 700,000 informal carers in the UK supporting people living with dementia. ³

The financial cost of dementia

The total costs of dementia in the UK in 2019 amount to £34.7 billion at 2015 prices. This is set to rise sharply over the next two decades, to £94.1 billion in 2040.¹ The number of people with severe dementia is projected to more than double, and the costs of social care are projected to nearly triple by 2040.²

Health care accounts for £4.9 billion (14%) of the total costs in the UK, whereas social care (publically and privately funded) is £15.7 billion (45%) and unpaid care £13.9 billion (40%). ²

This strategy is underpinned by the National Dementia Strategy and sets out the strategic direction for dementia services for people living in Stoke-on-Trent up to 2024 and beyond and will be used to inform and determine our commissioning, service planning and development for each year for the life of the strategy.

Once new development plans have been agreed, the Stoke-on-Trent and North Staffordshire Dementia Steering Group will retain responsibility for overseeing local strategic delivery/action plans.

Sources:

1. England and Wales; Mortality Statistics: Deaths Registered in England and Wales (Series DR). Scotland: National Records of Scotland Vital Events Reference Tables. Northern Ireland; Northern Ireland Statistic & Research Agency Registrar General Annual Report
2. 'Projections of care for older people with dementia in England: 2015 to 2040' published in 2019 by the Care Policy and Evaluation Centre', funded by Alzheimer's Society.
3. Lewis et al (2014) Trajectory of Dementia in the UK



National and local guidance and policy context

National

‘**Living Well with Dementia: A National Dementia Strategy**’, published in 2009 by the Department of Health, provides the national framework for improving the local development and delivery of services to people affected by dementia. The following three key areas were outlined for specific note:

- improved public and professional awareness
- access to earlier diagnosis
- support and empowering people to live well with dementia.

The strategy identifies 17 objectives, the majority of which are for local implementation, whilst ensuring that dementia pathways were closely aligned to other mental health services.

In 2012 the Prime Minister’s Challenge on Dementia 2012-15 was launched, building on the work of the national strategy. The Challenge aims to make England, by 2020, the best country in the world for dementia care, support, research and awareness. Its commitments are split across four themes: risk reduction, health and care, awareness and social action, and research. Many of them can only be met through the joint efforts of multiple organisations.

In February 2015 the Prime Minister launched the Challenge on Dementia 2020. This summarised the progress since 2012 and was followed in 2016 by an Implementation Plan. The plan details actions for fulfilling key commitments by 2020 and features the Well Pathway for Dementia (see appendix 1).

The Well Pathway for patients with dementia focusses on:

- preventing well
- diagnosing well
- supporting well
- living well
- dying well



The Dementia Statements, developed originally to inform the first Challenge on Dementia, reflect the things people with dementia have said are essential to their quality of life. Covered within human rights law, the Dementia Statements are developed to improve the lives of people with dementia and to recognise that they shouldn't be treated differently because of their diagnosis.

The person with dementia is at the centre of these statements:

- We have the right to be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it.
- We have the right to continue with day to day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness.
- We have the right to an early and accurate diagnosis, and to receive evidence-based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live.
- We have the right to be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future.
- We have the right to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and be supported to take part.

NHS Long Term Plan was published in January 2019 and set out a 10 year practical programme of phased improvements to NHS services and outcomes. With regards to dementia the plan states that “we will go further in improving the care we provide to people with dementia and delirium, whether they are in hospital or at home.” “We will continue working closely with the voluntary sector, including supporting the Alzheimer’s Society to extend its Dementia Connect programme which offers a range of advice and support for people with a dementia diagnosis.

In addition to the drive to transform dementia services, there has been continued focus across all health and social care services on supporting people’s choice and to develop and deliver services that are responsive and personalised to the needs of the individual.

The NICE guideline [NG97], published in June 2018, covers diagnosing and managing dementia (including Alzheimer’s disease). It aims to improve care by making recommendations on training staff and helping carers to support people living with dementia.

The Care Act 2014 places responsibilities on local authorities to improve individual's independence and wellbeing including:

- promoting the wellbeing of individuals
- promoting integration of health and social care services
- providing or arranging preventative services which reduce, prevent or delay the need for care and support
- providing information and advice relating to care and support available locally
- promoting diversity and quality in provision of services
- co-operating with partner organisations
- carrying out assessments where it appears that an adult may have needs for care and support
- adhering to new rights to support for carers, on an equivalent basis to the people they care for
- adhering to a national eligibility threshold setting one national level at which needs are great enough to qualify for funded services
- providing continuity of care for individuals moving between authorities
- having transparent charging policies

NHS England Implementation guide and resource pack for dementia care was published in July 2017. The overall aim of the document is to ensure that people with dementia and their carer's receive good care and support, meaning that no one has to wait months for an assessment of dementia.

NHS England Dementia: Good Care Planning was published in February 2017. This document is designed to help improve care planning in dementia by supporting a standardised approach, highlighting good practice, ensuring alignment with relevant cross-condition care plans and help to reduce local variation in the process.

My future wishes Advance Care Planning is for people with dementia in all care settings. Published by NHS England in April 2018, it provides signposting, information and support for colleagues in health, social and community care settings, around advance care planning for people living with dementia. It identifies key actions from the point of an initial diagnosis of dementia through to the advanced condition, in order to highlight and prompt best practice irrespective of care setting.

The Deprivation of Liberty Safeguards (DoLS) began in April 2009 and form part of the Mental Capacity Act 2005 which governs the care, treatment and finances of adults who lack capacity to make decisions in these areas. DoLS is designed to legally authorise restrictive care arrangements for adults lacking capacity to consent to them. A person must meet the required DoLS criteria and be in a care home or hospital setting. In May 2019 The Mental Capacity Amendment Act, which will introduce new Liberty Protection Safeguards to replace DoLS, received Royal Assent. It broadens the scope of safeguards to any setting, but the planned implementation in October 2020 is likely to be delayed.

Social prescribing and community-based support is part of the NHS Long Term plan's commitment to make personalised care business as usual across the health and care system. Social prescribing enables all local agencies to refer people to a link worker. Link workers give people time and focus on what matters to the person as identified through shared decision making or personalised care and support planning. Link workers connect people to community groups and agencies for practical and emotional support. They can also collaborate with local partners to support community groups to be accessible and sustainable and help people to start new groups.

Local guidance

'**Older People Mental Health, Stoke-on-Trent, Joint Strategy 2008-2013**' was published in 2008. It is a joint health and social care strategy incorporating plans for service development for people affected by dementia. It was supported in 2009, by the development of a local implementation/action plan, to deliver services against the objectives laid out in the National Dementia Strategy.

In 2010 consultation on the redesign of adult and older people's mental health services commenced, the main aim was to promote the delivery of mental health care closer to home achieved by introducing radical change to the way mental health services are locally provided.

The key principles required of all care services, based on national and local consultations were defined in previous policy frameworks as:

- Local and accessible services: Care closer to home
- Preventative: Focused on early intervention and prevention
- Choice: People have genuine choice of provision
- Independence: Services which promote independence

Local Clinical Commissioning Group in 2019/20 aims to 'continue to focus on improving the care of our growing elderly population' and to 'work within our Sustainability and Transformation Partnership (STP) – Together We're Better'. A Five Year Plan is currently being produced and the vision of the STP is to support:

- people to live well for longer and as independently as possible
- treating people as a person, not a set of health conditions or social care needs
- making sure doctors and nurses are there when they are needed at the right time and in the right place
- making services available closer to home
- giving mental health equal priority to physical health and well being
- making sure patient's experience of health and care is the best it can be
- making it easier for organisations to work together to increase efficiency

Stoke-on-Trent Joint Carers Strategy 2014-2018 will be reviewed in 2020 and developed in partnership with the Stoke-on-Trent City Council, Stoke-on-Trent Clinical Commissioning Group, carers, voluntary and community organisations. It will continue to provide a framework for a more holistic, integrated approach to supporting all carers. The strategy will outline the key priorities for carers over the next 4 years; many carers of people with dementia are older people themselves, who may have physical or learning disabilities, frailty and health conditions of their own.

The Better Care Fund (BCF) was announced in the governmental spending review of June 2013. The BCF is a pooled budget between Stoke-on-Trent Clinical Commissioning Group (CCG) and the City Council. The purpose of the funding is to:

- Drive forward agendas for the integration of the commissioning and delivery of NHS and social care services to better meet the needs of vulnerable people.
- Ensure that services (especially those associated with pressures on the acute sector, and urgent care) are planned 'end to end', and operate in an efficient, coordinated and coherent way.
- 'Protect' elements of the whole system (specifically social care) in the context of significant financial challenges

There are a number of national conditions set in the development and delivery of the BCF plan. These are:

- plans to be jointly agreed
- protection for social care services, as part of agreed local plans
- 7-day working in health and social care to support patients being discharged and prevent unnecessary admissions at weekends
- better data sharing between health and social care
- ensure a joint approach to assessments and care planning
- ensure that, where funding is used for integrated packages of care, there will be an accountable professional
- risk-sharing principles and contingency plans if targets are not met

The Joint Health and Wellbeing Strategy for Stoke-on-Trent 2016 – 2020, developed in collaboration across all partners, identified 'keeping older people safe and well' as a priority area. This identifies that the local authority will undertake a programme of work that will help people to live well with dementia.

People in Stoke-on-Trent told us

The 2015-19 strategy was developed following extensive consultation on local dementia services and support. During summer 2019 further consultation took place to refresh the strategy for 2020-24. The 2019 consultation explored whether the original priorities remain valid and whether work needed to have a different focus for the coming years. Those who responded remain supportive of the priorities and actions.

Local people told us they want:

- evolving, personalised and flexible services
- more coordinated services/ better partnership working
- quality services that are monitored
- better information, and improved access to information and support
- early diagnosis and referrals to happen quickly
- communities to be dementia aware
- more services, better access and greater investment
- awareness raising to change perceptions
- a workforce is appropriately skilled to support people with dementia
- timely diagnosis and access to services that help them live well
- good end of life support
- people living with dementia and their carers to be engaged in shaping and developing services



Population and data

National picture

It is estimated that there were almost 885,000 older people living with dementia in 2019. This is projected to increase by 80% to around 1.6 million in 2040.¹

Two thirds of people living with dementia are women. Women are more likely than men to develop dementia in their lifetimes. One of the main reasons for this is the longer life expectancy of women.² 537, 000 people in the UK have a dementia diagnosis.³

Not everyone with dementia has a diagnosis. This can be due to a number of factors including difficulty diagnosing in the early stages, the slow progression and limited public awareness of the diseases that cause dementia.

The dementia diagnosis rate in the UK was 66% in 2017/18.³

The diagnosis rate is calculated by dividing the number of people diagnosed with dementia by the total estimated number of people living with dementia.

One in three people born in the UK this year will develop dementia.⁴

Older People living with dementia

Although dementia can affect people of any age it is most common in older people. A person's risk of developing dementia rises from one in 14 over the age of 65, to one in six over the age of 80. 7.1% of all people over the age of 65 have dementia.² This is expected to reach 8.8% in 2040.

The prevalence rate and number of people with dementia in the UK is driven by an aging population. The Office of National Statistics population projections report that, while the number of older people aged 65-74 in the UK will increase by 20% between 2019 and 2040, the number of older people aged 85 and over will increase by 114%.

95% of people living with dementia are over 65 years old which is often referred to as late-onset. The prevalence continues to increase with age as two thirds of people living with late-onset dementia are over 80 years old. It is estimated that if all remains constant, the number of people living with late onset dementia will increase by 164% in the next 38 years.

Late onset dementia is more prevalent in women in the UK - 2013 there were 506,430 women compared to 267,072 men over 65 living with dementia.

It is also estimated that almost two thirds of people living with late-onset dementia are living within their communities (61.3%), with just over one third of people living in care homes (38.7%).

Younger people living with dementia

It is a common misconception that dementia is a condition of older age. At least 42,000 people in the UK aged under 65 years have dementia. That is more than 5% of all those with dementia.²

Early-onset or young-onset is used to describe the number of people living with dementia who are under 65 years old. Younger people with dementia may have different needs and issues to overcome than someone experiencing late-onset dementia. For example they may still be working and have dependents and are more likely to have a rarer form of dementia.

The Alzheimer's Dementia UK report (2014) estimated the following severity levels for people living with late onset:

- 55.4% are living with mild dementia
- 32.1% are living with moderate dementia
- 12.5% are living with severe dementia

1 in 20 people living with dementia are aged under 65 (Alzheimer's Society 2014)

Mortality and dementia

16.3% of women and 8.7% of men died due to dementia in 2017 in the UK. This was the leading cause of death for women and the second leading cause of death for men. In the UK, dementia is the only condition in the top 10 causes of death without a treatment to prevent, cure or slow its progression.⁵

Carers of people living with dementia

Caring for a family member living with dementia can be challenging, rewarding, change family relationships and impact on physical and psychological health. Recent evidence suggests that there are around 700,000 informal carers supporting the 850,000 people living with dementia in the UK.⁶

60-70% of carers for people with dementia are women. One in five female carers have gone from full time to part time employment as a result of their caring responsibilities and 17% felt penalised at work. ⁷

One third of carers spend more than 100 hours per week caring for a person with dementia. One in three carers for people with dementia had been doing so for between 5 and 10 years and one in five had been doing so for over 10 years.⁸

63% of carers for people with dementia are retired while 18% are in paid work. 15% of dementia carers say they are not in work because of their caring responsibilities. 36% of carers spend more than 100 hours per week caring for a person with dementia.⁹

People with a learning disability

Dementia in people with learning disabilities is becoming more common. This is because:

- Dementia becomes more common as people get older and people with learning disabilities are living longer.
- People with a learning disability are 5 times more likely to develop dementia as they get older compared to the general population.
- People with Down's syndrome have a specific additional risk of developing dementia. For them, this often happens at ages from 35 to 45 onwards. ¹⁰

The number of people in Stoke-on-Trent with a diagnosis of dementia and learning disability is low, and will increase over time but not significantly. The Stoke-on-Trent Joint Strategic Needs Assessment identified the following priorities to ensure that people with a learning disability/dementia and their carers have access to the right care and support with robust pathways in place to ensure that individuals receive 'person centred' coordinated care as their illness progresses and their needs change:

- To continue to work with current care providers to raise awareness of dementia/ learning disability
- Wider workforce development including dementia training for learning disability staff, awareness of environmental factors within the home and identifying any specific training requirements
- Pathway development
- Timely advice, information and support

During 2009, the Royal College of Psychiatrists published a report quoting dementia prevalence rates for; people with Down's syndrome and for people with a learning disability without Down's syndrome. For people with Down's syndrome prevalence rates of the general population were:

- Age 30-39 Prevalence Less than 10%
- Age 40-49 Prevalence 10-25%
- Age 50-59 Prevalence 20-50%
- Age 60+ Prevalence 30-70%

Public attitudes towards dementia

Awareness of dementia is increasing but understanding of the diseases that cause it remains low. One in five adults think dementia is an inevitable part of getting older. 41% of UK adults say that dementia is the health condition they fear most about getting in the future, including 51% of over 65s.¹⁰

More than half of the UK public has been affected by dementia.

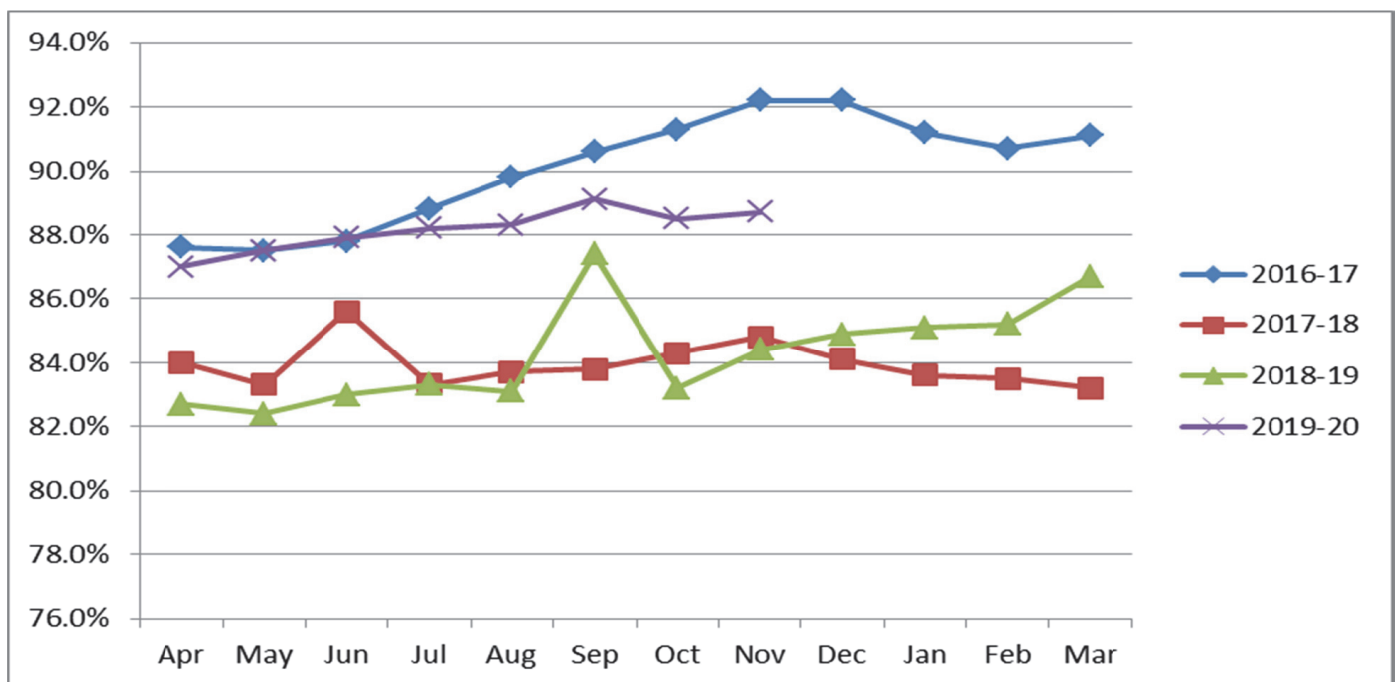
Population and prevalence in Stoke-on-Trent

While there has been increasing knowledge and understanding around the prevalence of dementia, a key issue is the disparity between the numbers of people thought to be living with dementia and those that have received a diagnosis. A diagnosis of dementia enables people to access support and treatment to help them to live well with the condition, and improving diagnosis rates has been a key priority nationally for a number of years.

Since the 2015-19 strategy Stoke-on-Trent has continued to close the gap between the estimated number of patients thought to be living with dementia. The prevalence is now calculated from the over 65+ patients on a GP register and this information is downloaded on a monthly basis providing a very accurate prediction.

Diagnosis rates for a particular area or population can then be calculated by comparing the difference between the expected numbers of people with dementia to the actual number of people on the populations GP Dementia Register.

Diagram - Dementia diagnosis rates in Stoke-on-Trent



The diagram shows that diagnosis rates for Stoke-on-Trent have exceeded the national target of 66.7% for some time.

Table 1 shows the estimated number of people living with dementia in 2020 by gender and age. Similarities can be seen with the national picture - the number of people living with dementia increases with age and a higher proportion of people living with late on-set dementia are female. It is projected that the number of people living with dementia in Stoke-on-Trent will have increased from 3011 in 2020 to 4128 in 2035 – an increase of over one third (37%). See table 1 and table 4 below.

Table 1: Number of people in Stoke-on-Trent predicted to have dementia in 2020

Source: Dementia UK 2014 (via PANSI and POPPI websites)

Gender		Male	Female	Total
Age	>65	39	26	65
	65-69	92	115	207
	70-74	186	192	378
	75-79	223	310	533
	80-84	268	398	666
	85-89	196	424	621
	90+	118	425	542
Total		1121	1890	3011

Table 2: The rates for men and women with dementia in Stoke-on-Trent

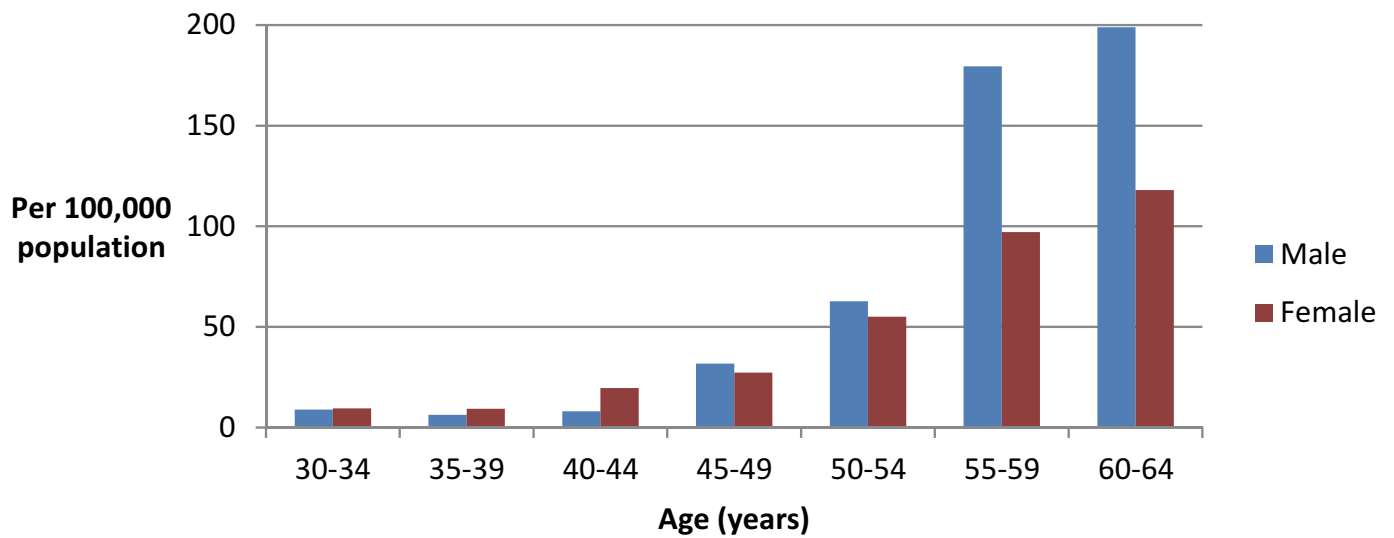
Source: Dementia UK 2014 (via PANSI and POPPI websites)

Gender		Male	Female
Age	>65	See table 3	See table 3
	65-69	1.5%	1.8%
	70-74	3.1%	3%
	75-79	5.3%	6.6%
	80-84	10.3%	11.7%
	85-89	15.1%	20.2%
	90-94	22.6%	33%
	95+	28.8%	44.2%

Table 3: The rates for early onset dementia (per 100,000)
 Source: Dementia UK 2014 (via PANSI and POPPI websites)

Gender		Male	Female
Age	30-34	8.9	9.5
	35-39	6.3	9.3
	40-44	8.1	19.6
	45-49	31.8	27.3
	50-54	62.7	55.1
	55-59	179.5	97.1
	60-64	198.9	118

Diagram - Rates for men and women with early onset dementia in Stoke-on-Trent



The diagram shows the number of males and females per 100,000 of population diagnosed with early onset dementia.

Table 4: Number of people in Stoke-on-Trent estimated to have dementia by 2035

Source: Dementia UK 2014 (via PANSI and POPPI websites)

Gender		2005	2035
Age	Under 65	66	60
	65 - 69	223	251
	70 - 74	348	424
	75 - 79	641	653
	80 - 84	764	897
	85 - 89	691	1029
	90+	542	813
	Total	3275	4128

The Stoke-on-Trent Joint Strategic Needs Assessment (JSNA) 2019 outlines that, whilst there have been improvements across a number of key health outcomes in Stoke-on-Trent in recent years, the health of local people is generally worse than the England average. The prevalence of dementia and other severe mental health conditions were higher locally compared to England.

The JSNA reports by 2030 the number of people aged 65 and over living in Stoke-on-Trent are projected to increase by around 9,300 to 52,400. This means that nearly 1 in 5 local people (19.9%) will be aged 65 and over (compared with 16.9% currently). This progressively older population will mean the numbers of people with increasingly complex and long-term conditions, such as dementia, will continue to grow. This in turn will impact on the need and provision for social care support.

Loneliness can be felt by people of all ages, but as people get older, the risk factors that can lead to loneliness (such as poor health, loss of mobility, becoming a carer) increase. Loneliness is harmful to our health. Lonely people are more likely to suffer from dementia, heart disease and depression. Loneliness increases the likelihood of dying by around 25%.

The proportion of local people with dementia is predicted to rise by over one third by 2030.

Sources:

1. 'Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019–2040', Care Policy and Evaluation Centre, London School of Economics and Political Science
2. Prince, M et al (2014) Dementia UK
3. NHS Digital; Recorded Dementia Diagnosis Data
4. Lewis, F: Estimation of future cases of dementia from those born in 2015 (July 2015); Consultation report for Alzheimer's Research UK
5. England and Wales; Mortality Statistics: Deaths Registered in England and Wales (Series DR). Scotland: National Records of Scotland Vital Events Reference Tables. Northern Ireland; Northern Ireland Statistic & Research Agency Registrar General Annual Report
6. Lewis et al (2014). Trajectory of Dementia in the UK
7. Women and Dementia: A Marginalised Majority by Alzheimer's Research UK
8. Personal Social Services Survey of Adult Carers in England, 2016-17
9. Personal Social Services Survey of Adult Carers in England, 2016-17; NHS Digital
10. Making Reasonable Adjustments to Dementia Services for people living with disabilities, September 2013
11. Dementia Attitudes Monitor 2019

Vision and priority areas for action

In Stoke-on-Trent we want people living with dementia and their carers to live in a city where they:

- feel included in society
- are empowered and able to make decisions about their future
- are treated with dignity and respect and that people around them have an understanding and awareness of dementia
- can access high quality, personalised care and support services
- know they will be (were) diagnosed in a timely way
- know where to go for the right information advice and support

The Stoke-on-Trent Joint Dementia Strategy was developed by Stoke-on-Trent City Council and Stoke-on-Trent Clinical Commissioning Group in partnership with health, voluntary and community organisations. This strategy, in line with the national strategy and local consultation and guidance, sets out our key priorities over the next four years and will inform the strategic planning, service delivery and commissioning of support for people with dementia and their carers living in Stoke-on-Trent.

Our Vision is to create a dementia friendly community that helps to improve the quality of life for people with a diagnosis of dementia and their carers. We will ensure that people are supported to live well with dementia through working together with service users, carers and partner organisations to continue to deliver the National Strategy at a local level.



Priority 1 - Spread the message of 'living well' - Improve professional and public awareness of dementia

Improve professional and public awareness of dementia.

National strategy and guidance suggests an overall lack of both public and professional awareness of dementia and highlights the impact this can have on a person's ability to live well with dementia. Misconceptions that 'dementia is a natural part of ageing' or 'that nothing can be done' can prevent people from seeking a diagnosis and the necessary help and support.

Dementia is the condition that people over the age of 55 fear most - more so than cancer or heart disease and there is a belief that society is not geared up to deal with the condition. Research shows that people living with dementia have reported feeling lonely, and a loss in friendships and while almost two-thirds of people living with dementia are within their communities a research study showed that less than half of their respondents felt part of their communities.

Whilst good progress has been made since the launch of the National Dementia Strategy and the Prime Ministers' Challenge on Dementia, in May 2014 Public Health England in partnership with Alzheimer's Society launched the Dementia Friends Campaign with the aim of reducing fear, improving public and professional understanding and awareness of dementia.

Progress to date

Awareness raising campaigns - partners promote and take part in dementia awareness campaigns. In support of the annual national Dementia Action Week, partners across Stoke-on-Trent and North Staffordshire join together for a local awareness campaign. In 2019 two key events, co-ordinated on behalf of the Dementia Steering Group, provided information and advice to local residents. 12 organisations had stalls in Longton's indoor market and many also exhibited at Affinity Outlet (shopping centre) in Talke. The success of these is shaping plans for future events.

The Stoke-on-Trent and North Staffordshire Dementia Steering Group – has developed and continues to provide the local steer for commissioning and the development of services for people who are living with dementia and their carers. The steering group has members representing people living with dementia, statutory and voluntary sector services. The group has been involved in the review of the local joint dementia strategy 2015-19 and has led other key pieces of work to enable people living with dementia and their carers to live well.

Engaging people with dementia – through the steering group and other forums more people affected by dementia have been enabled to be engaged in debates and influence local strategies and plans.

Improving networking and practice – the Dementia Network Staffordshire and Stoke-on-Trent, formerly the Staffordshire and Stoke-on-Trent local Dementia Action Alliance, has continued to develop to enable local members and interested parties to share best practice and become more dementia friendly. For 2020 and beyond the network is strengthening its approach to supporting more local areas in their journey to be working towards Dementia Friendly Communities status.

Changing perceptions of dementia – Over 800 Dementia Friends sessions have taken place in the city, helping people affected by dementia and others in the community to learn and change their perceptions of dementia. People have also taken part in online training. By 2019 there were 16,000 Dementia Friends and 36 people trained as Dementia Champions – they are volunteers who encourage others to make a positive difference to people affected by dementia.

Improving communications – a frequent Dementia Bulletin has been set-up by the local authority to share news and information with over 2700 people, including professionals and people living with dementia.

NHS Health Check – dementia risk reduction messaging was incorporated in the NHS Health Check in 2013 for everyone eligible, aged 40-74. Promoting the concept of ‘what’s good for the heart is good for the brain’, the NHS Health Check dementia leaflet is available to support the dementia information given to those who attend an NHS Health Check appointment. The number of NHS Health Checks undertaken each year: 7,133 in 2016-17; 7,463 in 2017-18; and 7,815 in 2018-19.

Hospital dementia care - University Hospitals of North Midlands NHS Trust (UHNM) are working to improve dementia care in the following areas:

- Dementia Action Week events were held at both sites with lots of teams and professionals getting involved and gaining fantastic and valuable feedback on services and their future development.
- Dementia training takes place at both sites and meetings have taken place to review the training delivered.
- The care coach team have developed a dementia competency booklet that can be used for registered and un-registered staff at UHNM.
- The dementia butterfly scheme was re-launched at the trust during 2019.
- The Mental Health Liaison Team are holding delirium clinics – ensuring that all patients at the Royal Stoke University Hospital are reviewed by a mental health professional.
- Joint work with local voluntary organisations to deliver Dementia Friends training and hold stalls at UHNM to raise awareness and provide support patients, carers and staff.

Next steps

In Stoke-on-Trent we want to create a community where people living with dementia and their carers are empowered, met with understanding and can honestly say that 'they feel included as part of society'. We want to raise public understanding about dementia to reduce fear and encourage people to seek help and support and to ensure that professionals are also appropriately skilled and dementia aware.

We will continue to:

- Raise awareness about dementia in communities including key organisations and businesses, ensuring that key messages around dementia are consistent, relevant, timely and positive.
- Raise awareness about the importance of prevention and early intervention, including self-help and lifestyle interventions to reduce vascular risk factors.
- Raise awareness about national and local developments in research and opportunities.
- Support people living with dementia to have a voice within their communities and have an active role in the development of dementia friendly communities.
- Ensure plans focus on priorities identified locally.
- Develop the workforce within Stoke-on-Trent:
 - To create a workforce that is dementia aware.
 - To ensure that staff directly providing care and support services are fully skilled in providing the highest level of care and support to people with dementia and their carers.
 - To support health professionals to provide good information and advice to individuals, their carers and families.
 - To change culture and ensure that all staff/organisations are confident and skilled in delivering 'person centred' care and support.
 - To raise the quality of care delivered by more standardised training and up-skilling all staff and positioning dementia care as core competency in their roles.
 - To explore more standardised training for those working with people affected by dementia, including opportunities to incorporate people affected by dementia.

Appendix 3 provides further detail on the workforce aspirations for social care and health service providers.

Priority 2: Timely diagnosis and support

For people to receive a diagnosis in the right way, at the right time, with access to the right support

Local and national strategy and consultation highlights the need for people with dementia to have access to a timely diagnosis and appropriate support. In 2013 it was estimated that less than half of people living with dementia in England had a formal diagnosis (or were known to specialist services). A timely diagnosis is important as a diagnosis can often occur at times of crisis or when the dementia is in the later stages. This limits a person's ability to make important choices and can lead to early admissions into long-term care that could have been avoided.

A timely diagnosis is key to enabling people with dementia and their carers access to the best possible support, treatment and care and can empower people living with dementia to plan and make decisions about their own future.

Progress to date

Data Quality Facilitators – continue to work with GPs to ensure that dementia registers are accurate and up to date and to help identify where performance is lowest.

Dementia diagnosis rates – through local health economies working together, the diagnosis rates for Stoke-on-Trent have exceeded the national target of 66.7% for some time. They have continued to improve over the years as shown in the diagram on page 11. As of October 2019, Stoke-on-Trent Clinical Commissioning Group has the fourth best diagnosis rate out of 191 CCG's across the country.

The diagnosis figures dropped at the end of the financial year 2016-17 due to NHS England changing the way that the diagnosis rates were collected. From this point on, the figures only included patients aged 65 and over, which accounts for the drop in diagnosis rate at the start of 2017-18. There was also a dip in the diagnosis rate figure in September 2018 which was reflected across all CCG's and rectified itself in the October 2018 information.

Local memory support service – the local service was reviewed and commissioned for April 2019 onwards. Alzheimer's Society provides the new service, known as Dementia Connect. Upon diagnosis of dementia patients and their carer(s) will be referred to Dementia Connect to help them manage their condition and live independently for longer. The service combines face-to-face support with telephone, written and online advice and information offered by specially trained Dementia Advisers. A service called Side by Side may be offered to help reduce loneliness and increase confidence.

Local dementia pathways - the Northern Staffordshire Memory Services Pathway Group was set up in 2019 to support the work of the Dementia Steering Group. It has an operational focus to ensure the dementia patient and carer pathway is working well across North Staffordshire and Stoke-on-Trent. The group has mapped the local dementia support pathways – these are summarised in appendix 2. Work is underway, through the pathway group, to review the information issued to those attending the local memory clinic.

Dementia Advocacy Service – is commissioned to assist and support 84 people with dementia and memory impairment to communicate, exercise and defend their rights and to fully participate in the many decisions affecting their lives. The service, provided by Beth Johnson Foundation, has provided specialist support to people with dementia at key times of transition and change.

Next Steps

Within Stoke-on-Trent we want to continue to improve the quality of life for people with dementia by ensuring that people have access to the right information and advice and support to empower people to make informed decisions regarding their future.

We want people in Stoke-on-Trent to be able to honestly say that they were ‘diagnosed in a timely way’ and have access to the most appropriate treatment and support. By continued review and re-design our Memory Services and through monitoring and evaluating our support services our priorities are to ensure that:

- Diagnosis rates continue to increase as diagnosis is made within a timely manner and is diagnosed well by compassionate and appropriately skilled staff.
- People have access to the appropriate support at diagnosis (including access to relevant information, advice, care and support).
- Diagnosis rates are consistent across the city, with lower performing areas targeted for improvement.



Priority 3: Enable people to live well with dementia

Access to high quality, personalised support for both the person with dementia and their carers

It is recognised that with access to the right information, treatment, support and care people can live well with dementia.

Two out of three people with dementia live within their communities. Access to personalised appropriate community support services is vital to enable people to live well within their communities and remain as independent as possible. Evidence suggests that while people wish to remain in their own homes, all too often crisis situations arise which can result in avoidable or early admissions to hospital or long-term care due to a lack of appropriate support within the community.

When in hospital people with dementia are reported to stay there longer and it is recognised a person's symptoms may be amplified due to their environment and people may feel too unwell and low to return home and opt for long-term care which could have been avoided.

Progress to date

Joint health and social care dementia service – as part of our re-design of dementia services, a specialist joint health and social care dementia centre was set up at Marrow House in 2015. The service offers bed based and community reablement services for people with dementia who require differing levels of support within the community. Integrated approaches and more flexible working arrangements provide more coordinated services; have improved reablement services; and improved access to information, advice and support.

Local memory support service – commissioned from April 2019, Alzheimer's Society's Dementia Connect service helps people manage their condition and live independently for longer. The service also supports people who care for those with dementia. Dedicated Dementia Advisers stay in touch throughout the person's dementia journey, helping them to access services and giving them on-going support to live well with dementia in the community. The service also provides a leaflet, called 'This is Me', for anyone receiving professional care who is living with dementia or experiencing delirium or other communication difficulties. 'This is me' can be used to record details about a person who can't easily share information about themselves and helps professionals deliver care that is tailored to the person's needs.

Hospice Admiral Nurses – in September 2018 Douglas Macmillan appointed its second Admiral Nurse and became the only hospice in the UK to have two specialist dementia nurses based in-house. The Admiral Nurse Service has been developed in partnership with Dementia UK.

Social Prescribing – following a local pilot involving local agencies referring people to local link workers, some primary care networks will continue to adopt this approach. Link workers have given people time and focus on what matters to the person and have connected people to community groups and agencies for practical and emotional support.

The Carers Hub - provide free support for adult and young carers (aged 5-18 years). They provide information, advice and guidance to relevant services. They will also provide a full assessment of need, assess if an application for a Personal Wellbeing Budget is needed to support the caring role and invite carers to groups and courses. The Carers Hub currently have been in contact with approximately 220 dementia carers across Stoke-on-Trent to provide support, information and guidance.

The Well Pathway for Dementia – this treatment and care pathway aims to ensure people have a better experience of health and social care support from diagnosis to end of life. Appendix 1 provides a detailed overview of the Well Pathway model. The diagram in appendix 2 shows the providers of services and support in Stoke-on-Trent for patients and carers at each stage of the pathway.

Reablement - Within Stoke-on-Trent there are specialist reablement/ intermediate care services available for people with dementia living within their community and approaching a crisis point or who are in hospital and are ready to be discharged. Reablement is usually provided for a limited period to help people remain independent by providing the opportunity to relearn or regain some of the skills for daily living that may have been lost as a result of illness. The services provides access to a multi-disciplinary team of professionals who can provide assessment and therapy support to help a person regain the skills and confidence they need to be able to return home or remain at home for longer. The services also provide a secure, supportive environment for people to make important decisions about the next stage in their lives and enable information and advice to be given to families and carers about the various options and support available.

For people with dementia and their carers who require on-going support there is also a wide range of services to support people throughout the whole pathway of living with a diagnosis of dementia. Appendix 2 identifies the local providers of support.

People who have concerns about Alzheimer’s disease or about any other form of dementia, are advised to contact the Alzheimer's Society National Dementia Helpline on 0300 222 112235. The helpline can provide information, support, guidance and signposting to other appropriate organisations.

Next steps

Both nationally and locally people told us they want access to coordinated, personalised services that will support not only the person with dementia but also the people that care for them. They have told us that access to clear information and advice and knowing where to go for help is really important. People also want services they can trust in, delivered by skilled people who understand about dementia.

We will continue to work to improve access to:

- specialist reablement services for people with dementia
- peer support groups
- information and advice
- services delivered by an effective workforce who are dementia aware or dementia skilled as appropriate
- support for younger people living with dementia
- support for people from minority groups living with dementia
- community based services following an episode of illness
- excellent end of life services
- social work support and assessment
- advocacy
- assistive Technology

We remain committed to engaging with people with dementia and their carers to enable them to inform and influence the support and services commissioned within Stoke-on-Trent.

A key priority will be to build on our work with partners including carers, people living with dementia, providers and commissioners to develop robust contract monitoring to ensure that services are meeting needs and are of the highest quality.



Workforce

The key development considerations for staff working with older people with mental health needs, including dementia, largely reflect the strategic moves for social care more generally. The demographic pressure and increasing prevalence of dementia will accelerate the need to move towards models of care that promote choice, increase independence and reduce or delay dependence on statutory services. Whilst a reablement service operates for people with dementia involving social care and health staff, the demand on this service along with the need for appropriate exit maintenance services, will undoubtedly increase. It is vitally important that these services understand best practice approaches that are key to delivering care to service users with cognition and capacity issues. It is also important that generic care services have a better understanding of the issues and the experiences faced by service users and carers. Often this lack of awareness leads to exclusion from services.

It has long been recognised that the attitudes, skills and knowledge of staff working with people with dementia have the potential to influence the person's well-being, quality of life and function. Appendix 3 identifies the three dementia stages and the workforce competencies for dementia applicable for all health care professionals.

A key component will be an increased use of person centred/outcome based assessment and care planning. This approach, used widely in services for younger people, is key for people whose needs must be understood in the context of their biographical history. This approach explores the whole range of needs, not just the perceived problems.

Similarly there is a low uptake of direct payments/individual budgets. Health studies are stressing the need for this approach to be embraced as personal assistants may well provide the opportunity for a more consistent and familiar care delivery for the future.

Staff need to be skilled and training available in the non-pharmacological approaches to caring for people with dementia especially in residential care and nursing homes, day opportunities and community settings. The health economy continues to work towards reducing the use of antipsychotic prescribing.

It is recognised that end of life care for people with dementia is an area in need of development. Whilst some people with dementia receive excellent end of life care there are many that don't receive appropriate care and support. At the end of their lives many people with dementia are denied a death where their dignity and comfort is paramount and families/carers can feel unsupported or uninvolved.

As a health and social care economy, we need to ensure that the workforce are appropriately trained and competent with regards to the 'Skills for Health End of Life Competencies' and 'National Occupational Standards' including: communication skills; assessment and care planning; advanced care planning; and symptom management, as they apply to end of life care. This will also involve assessment of education and training needs of organisations and the general workforce to ensure that staff are equipped with the skills, training and knowledge in end of life care for people with dementia.

There are a number of key points about the workforce that stand out both nationally and locally including:

- The social care workforce is growing in size and is predicted to grow to enable it to meet the increased demand, this however presents wider issues relating to the difficulties that are arising both locally and nationally around the recruitment and retention of care staff.
- The majority of the workforce is employed in the independent/private and voluntary sector.

In line with the national dementia strategy, we need to ensure that we have ‘An informed and effective workforce for people with dementia. Health and social care staff involved in the care of people who may have dementia have the necessary skills to provide the best quality of care in the roles and settings where they work. To be achieved by effective basic training and continuous professional and vocational development in dementia’.

Our vision is to improve the quality of life for people with a diagnosis of dementia and their carers and that people are supported to live well with dementia through ensuring that we have a confident, supported and well equipped workforce who will deliver truly person centred dementia care and support that:

- The dignity and care of individuals is respected at all times.
- People have maximum choice and control of their lives.
- Independence is maintained where possible.



Delivering the strategy

Stoke-on-Trent and North Staffordshire Dementia Steering Group

The Stoke-on-Trent and North Staffordshire Dementia Steering Group provides the local steer for commissioning and development of services for people who are living with dementia and their carers.

The aims and objectives of the steering group are to draw together all parties across health and social care provision including statutory, voluntary agencies, independent sector and users of services, to implement local and national priorities and strategy, to enable people living with dementia and their carers to live well.

The steering group is made up of people living with dementia and representatives from the following organisations:

- Age UK
- Alzheimer's Society
- Approach
- Beth Johnson Foundation
- Carers hub
- Diocese of Lichfield
- Douglas Macmillan Hospice (Admiral Nurse)
- Healthwatch Stoke-on-Trent
- North Staffs Carers Association
- North Staffordshire Combined Healthcare NHS Trust
- Staffordshire County Council
- Staffordshire Fire and Rescue Service
- Staffordshire Moorlands District Council
- Stoke-on-Trent City Council

In line with its aims, the group will oversee the implementation of the national and local dementia strategies, including this strategy.

A delivery plan will be developed to deliver this local strategy and will be subject to monitoring and annual review by the Stoke-on-Trent and North Staffordshire Dementia Steering Group.

Northern Staffordshire Memory Services Pathway Group

To support the work of the Dementia Steering Group, the Northern Staffordshire Memory Services Pathway Group was set up in 2019. Its focus is to ensure the dementia patient and carer pathway is working well across North Staffordshire and Stoke-on-Trent.

The group aims to draw together all parties across the health and social care provision, private, independent and voluntary agencies and users and carers. Members will identify issues and work together to implement changes to improve the dementia pathway for both patients and carers.

The membership of the group is:

- Patients and carers
- Commissioners
- Memory Support Service – Alzheimer’s Society
- Memory Clinic
- Marrow House
- Beth Johnson Foundation
- Approach
- Dementia Admiral Nurse
- University Hospitals of North Midlands NHS Trust

Dementia Network Staffordshire and Stoke-on-Trent (DNSS)

In addition to the local groups mentioned above, the Dementia Network Staffordshire and Stoke-on-Trent works to bring about a community wide response to dementia across the area. It is a group of local organisations, businesses and individuals who are committed to enabling people to live well with dementia by taking action to contribute towards the development of Dementia Friendly Communities.

Member organisations share equal responsibility for the DNSS and the group encourages and welcomes new members to join and be a part of the network.

Appendix 1: The Well Pathway for Dementia

The Well Pathway for Dementia is the treatment and care pathway that aims to ensure people have a better experience of health and social care support from diagnosis to end of life. The diagrams below show the providers of services and support in Stoke-on-Trent for patients and carers at each stage of the pathway.

NHS ENGLAND TRANSFORMATION FRAMEWORK – THE WELL PATHWAY FOR DEMENTIA

PREVENTING WELL	DIAGNOSING WELL	SUPPORTING WELL	LIVING WELL	DYING WELL
 <p>Risk of people developing dementia is minimised</p>	 <p>Timely accurate diagnosis, care plan, and review within first year</p>	 <p>Access to safe high quality health & social care for people with dementia and carers</p>	 <p>People with dementia can live normally in safe and accepting communities</p>	 <p>People living with dementia die with dignity in the place of their choosing</p>
<p>"I was given information about reducing my personal risk of getting dementia"</p>	<p>"I was diagnosed in a timely way"</p> <p>"I am able to make decisions and know what to do to help myself and who else can help"</p>	<p>"I am treated with dignity & respect"</p> <p>"I get treatment and support, which are best for my dementia and my life"</p>	<p>"I know that those around me and looking after me are supported"</p> <p>"I feel included as part of society"</p>	<p>"I am confident my end of life wishes will be respected"</p> <p>"I can expect a good death"</p>
<p>STANDARDS:</p> <p>Prevention⁽¹⁾ Risk Reduction⁽⁵⁾ Health Information⁽⁴⁾ Supporting research⁽⁵⁾</p>	<p>STANDARDS:</p> <p>Diagnosis⁽¹⁾⁽⁵⁾ Memory Assessment⁽¹⁾⁽²⁾ Concerns Discussed⁽³⁾ Investigation⁽⁴⁾ Provide Information⁽⁴⁾ Integrated & Advanced Care Planning⁽¹⁾⁽²⁾⁽³⁾⁽⁵⁾</p>	<p>STANDARDS:</p> <p>Choice⁽²⁾⁽³⁾⁽⁴⁾, BPSD⁽⁶⁾⁽²⁾ Liaison⁽²⁾, Advocates⁽³⁾ Housing⁽³⁾ Hospital Treatments⁽⁴⁾ Technology⁽⁵⁾ Health & Social Services⁽⁵⁾ Hard to Reach Groups⁽³⁾⁽⁵⁾</p>	<p>STANDARDS:</p> <p>Integrated Services⁽¹⁾⁽³⁾⁽⁵⁾ Supporting Carers⁽²⁾⁽⁴⁾⁽⁵⁾ Carers Respite⁽²⁾ Co-ordinated Care⁽¹⁾⁽⁵⁾ Promote independence⁽¹⁾⁽⁴⁾ Relationships⁽³⁾, Leisure⁽³⁾ Safe Communities⁽³⁾⁽⁵⁾</p>	<p>STANDARDS:</p> <p>Palliative care and pain⁽¹⁾⁽²⁾ End of Life⁽⁴⁾ Preferred Place of Death⁽⁵⁾</p>

References: (1) NICE Guideline. (2) NICE Quality Standard 2010. (3) NICE Quality Standard 2013. (4) NICE Pathway. (5) Organisation for Economic Co-operation and Development (OECD) Dementia Pathway. (6) BPSD – Behavioural and Psychological Symptoms of dementia.

RESEARCHING WELL

- Research and innovation through patient and carer involvement, monitoring best-practice and using new technologies to influence change.
- Building a co-ordinated research strategy, utilising Academic & Health Science Networks, the research and pharmaceutical industries.

INTEGRATING WELL

- Work with Association of Directors of Adult Social Services, Local Government Association, Alzheimer's Society, Department of Health and Public Health England on co-commissioning strategies to provide an integrated service ensuring a seamless and integrated approach to the provision of care.

COMMISSIONING WELL

- Develop person-centred commissioning guidance based on NICE guidelines, standards, and outcomes based evidence and best-practice.
- Agree minimum standard service specifications for agreed interventions, set business plans, mandate and map and allocate resources.

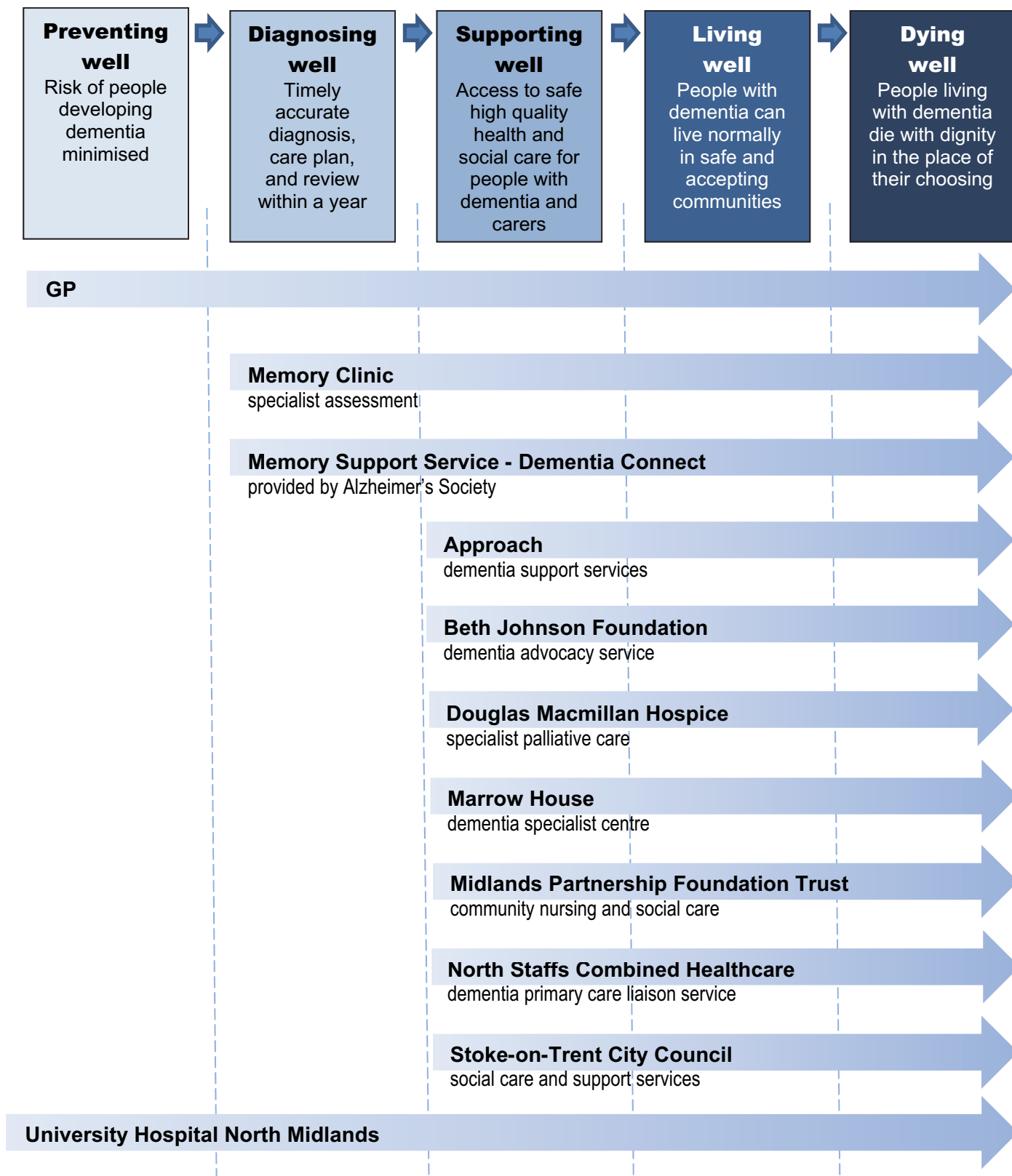
TRAINING WELL

- Develop a training programme for all staff that work with people with dementia, whether in hospital, General Practice, care home or in the community.
- Develop training and awareness across communities and the wider public using Dementia Friends, Dementia Friendly Hospitals/Communities/Homes.

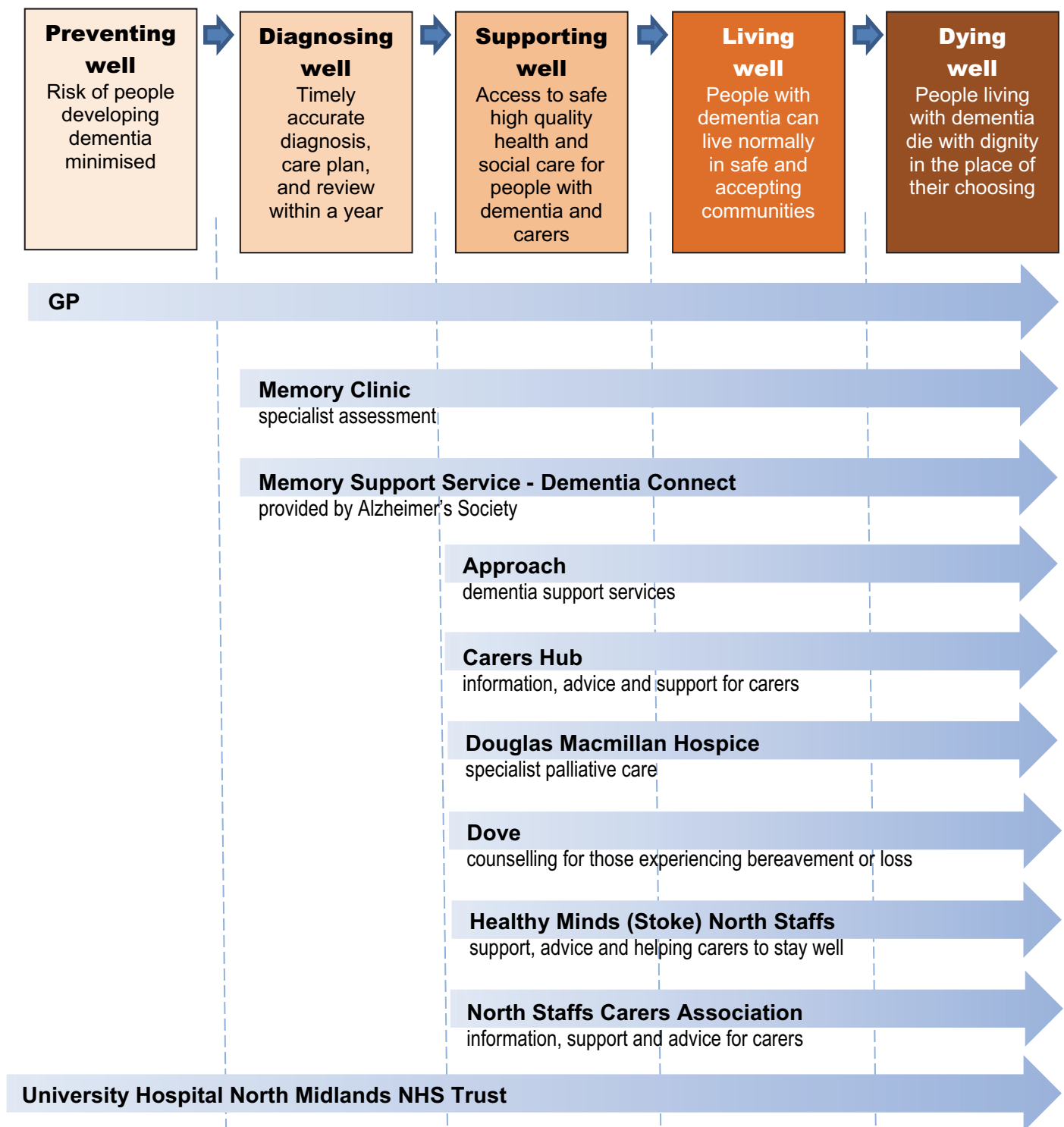
MONITORING WELL

- Develop metrics to set & achieve a national standard for Dementia services, identifying data sources and set 'profiled' ambitions for each.
- Use the Intensive Support Team to provide 'deep-dive' support and assistance for Commissioners to reduce variance and improve transformation.

Pathway for dementia patients in Stoke-on-Trent

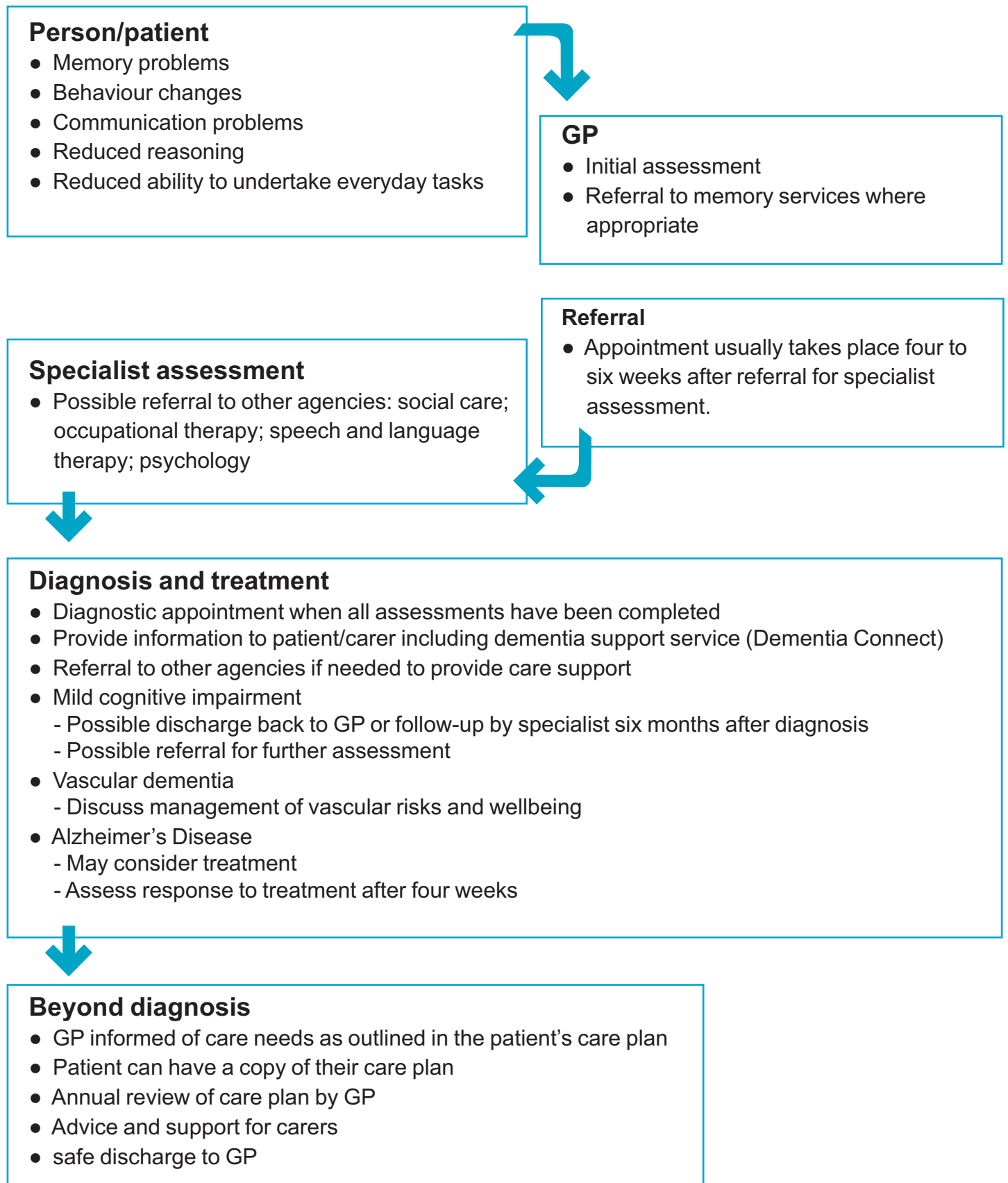


Pathway for dementia carers in Stoke-on-Trent



Appendix 2: Local dementia pathway

The diagram below outlines what someone can expect if they need to be referred to memory services within Stoke-on-Trent.



Appendix 3: Dementia stages and workforce competencies

Source: West London Mental Health <http://en.wikipedia.org/wiki/Dementia>

Stage: Mild cognitive impairment/early

In the first stages of dementia, the signs and symptoms of the disease may be subtle. Often, the early signs of dementia only become apparent when looking back in time. The earliest stage of dementia (actually, it is not even dementia, it could be considered pre-dementia) is called Mild Cognitive Impairment (MCI). 70% of those diagnosed with MCI will progress to dementia at some point. In MCI, changes in the person's brain have been happening for a long time, but the symptoms of the disease are just beginning to show. These problems, however, are not yet severe enough to affect the person's daily function. If they do, it is considered dementia. A person with MCI may have some memory trouble and trouble finding words but they solve everyday problems and handle their own life affairs well.

In the early stage of dementia, the person will begin to show symptoms noticeable to the people around them. In addition, the symptoms begin to interfere with daily activities. A person appears confused, and forgets about things that have just happened. They may not remember where they are, or what they did five minutes ago. Long-term memory is usually not much affected, and a person with dementia often talks about the past.

Concentration and decision-making become difficult, and mood changes are frequent. A previously happy person may become irritable or depressed over small things. Others may notice changes without understanding why.

Stoke-on-Trent GP guidelines

- Impaired by loss of memory for recent events.
- Some variable disorientation in time and place.
- Some difficulty with complex problems.
- Engaged in some activities but not independently.
- More difficult tasks and hobbies abandoned.
- Needs some prompting.

University Hospital of North Staffordshire

6 CIT 0-7 Inform GP of result on discharge

Stage: Moderate

As dementia progresses, the symptoms first experienced in the early stages of the dementia generally worsen. The rate of decline is different for each person.

The second stage, known as moderate dementia, brings more obvious confusion, forgetfulness and mood changes. A person may become anxious and aggressive. They may wander restlessly around the house and get up during the night. They may search the streets for a place or person from the past. They may also become suspicious of carers. Personal safety can be an issue, especially for those who smoke or cook. Even simple things like dressing can become difficult. The pressure upon carers is enormous as it becomes increasingly difficult to leave someone with dementia on their own.

If the person has Alzheimer's dementia, in the moderate stages almost all new information will be lost very quickly. The person may be severely impaired in solving problems and their social judgment is usually also impaired.

Hobbies that previously provided enjoyment may be abandoned.

University Hospital of North Staffordshire

6 CIT – 8 – 9 refer to medical team, inform GP on discharge advice, repeat 6 CIT after six months.

Stage: Severe

In the final stages of the illness, a great deal of help is needed (people tend to need 24 hour supervision). Long-term memory may still be strong, but often a person is unable to recognise those close to them, unable to talk properly, or understand what is said to them. Incontinence is common. During the later stages, most people become increasingly frail and may be confined to a wheelchair and then to bed. This makes them especially vulnerable to infections such as pneumonia.

He or she may have lost the ability to eat or swallow. Their appetite may decline to the point that the person does not want to eat at all. The person may be agitated.

University Hospital of North Staffordshire

6 CIT above 10 refer to RAID

Workforce competencies for dementia - all health care professionals

All health care professionals contribute of the stages of the dementia pathway to achieve; improve and sustain better outcomes so that all people with dementia, at all ages, are able to lead quality lives for longer.

Specialist support and advice may be required at any stage as a result of a person's complex needs. This will be specific to some health care professionals and additional to the work that all health care professionals do.

Dementia awareness

All health care professionals to have an awareness of dementia:

- Basic training
- Making every contact count
- Able to support and signpost public health messages

For example: district nurses, practice nurses, public health nurse, care workers, physio-therapists and occupational therapists.

Dementia skilled

All providing nursing to people with dementia directly

- All nurses that have more regular and intense contact with people with dementia, providing specific interventions, care and services.
- They have an enhanced knowledge and are skilled in dementia care.

For example: GP, consultant geriatrician, mental health nurse, liaison nurse, community matron, care home nurse, hospital nurse

Dementia specialist

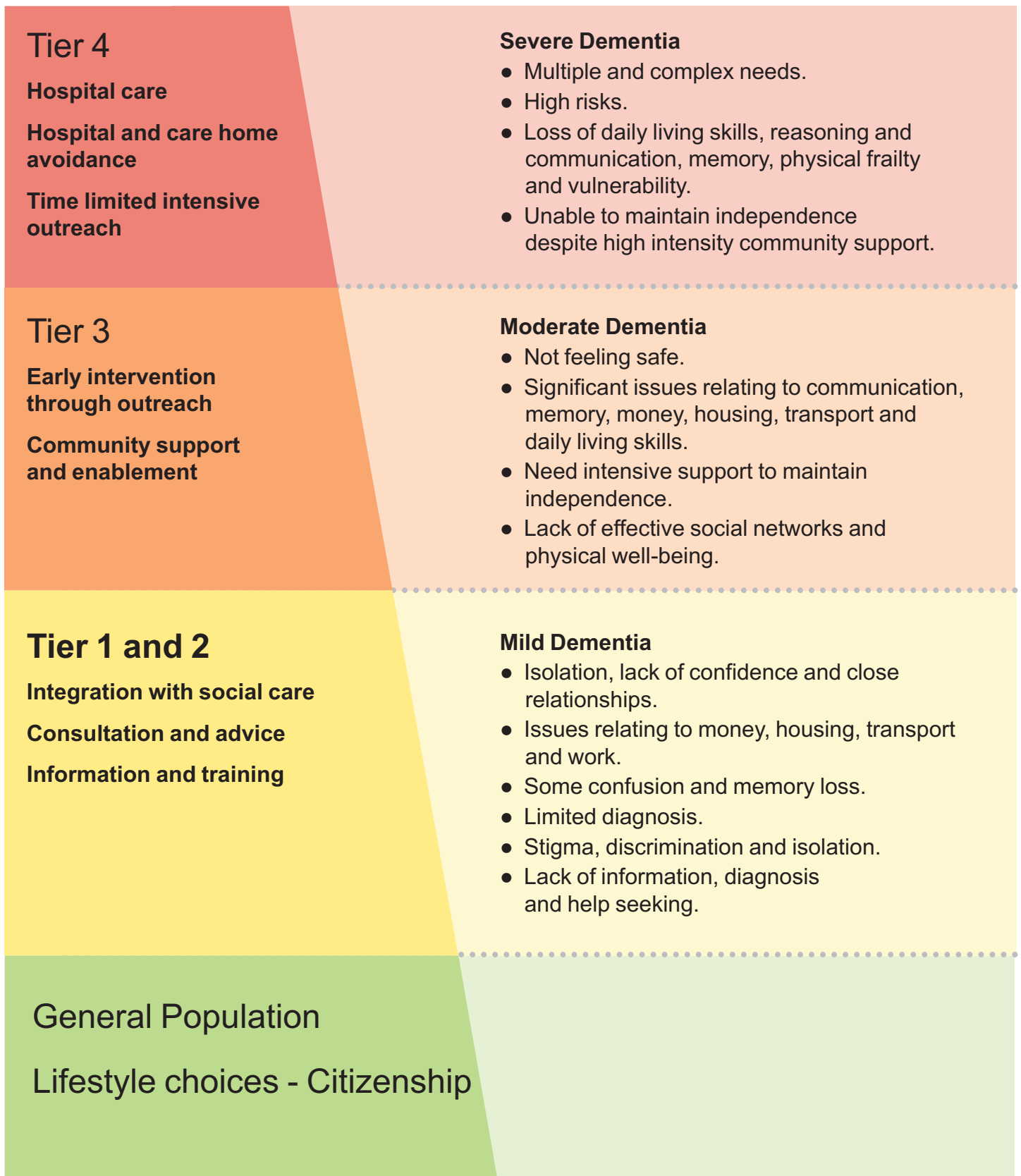
Experts in the field of Dementia care.

- Health care professional with an expert level of skill and knowledge/specialist role/dementia champions in the care, treatment and support of people with dementia, their carers and families.
- Their educative and consultative role aims to improve the delivery of dementia services delivering changes in practice.

For example: Consultant Old Age Psychiatry, admiral nurse, dementia specialist nurse

Appendix 4

Dementia Service tiers



Appendix 5: Dementia Friends in Stoke-on-Trent

Source: Alzheimer's Society

Dementia Friends is an Alzheimer's Society initiative that aims to change perceptions of dementia by transforming the way the nation thinks, acts and talks about the condition. People and organisations can learn more about dementia by attending a face-to-face information session or watch the online video. They will learn more about the disease and the ways they can help people living with dementia. There were 3 million Dementia Friends in the UK in 2019.

Dementia Friends Champions are volunteers who encourage others to make a positive difference to people living with dementia in their community. They do this by giving them information about the personal impact of dementia, and what they can do to help.

Dementia Friends in Stoke-on-Trent by postcode as at September 2019

Post code	Dementia Friends through organisations	Dementia sessions	Dementia Friends through face-to-face sessions	Dementia Friends through online route	Dementia Friends Champions
ST1	96	103	968	205	1
ST2	34	39	822	264	2
ST3	100	88	1082	523	6
ST4	141	202	4017	439	8
ST6	56	74	1191	465	1
ST7	54	145	2685	358	5
ST8	29	37	286	133	3
ST9	6	11	97	65	2
ST10	15	20	311	154	1
ST11	15	15	233	70	2
ST12	18	11	245	20	1
ST14	29	45	616	138	4
Total	593	808	12553	2834	36

16,800 Dementia Friends in Stoke-on-Trent

