# Experiences of Dementia and Memory Support Services in North Tyneside

## Detailed Report

### 1. Aim

The overall aim of this project is to further understand the key issues older people experience when using services for their mental health. **We want to know what is working well and what could be done better**. By doing so we will ensure service users and carers voices are represented in the pathway review with the intention to improve mental health services in the borough for people aged 65 and over.

This report focuses on older people's experiences of using services for their organic mental health, however, it is important to note that a number of people we spoke with discussed both their organic and functional mental health needs.

### 2. National Context

Approximately 850,000 people in the UK live with dementia[1]. When considering service provision, the Care Quality Commission (CQC) found that although quality of care for people with dementia was overall more good than bad, care was increasingly inconsistent[2]. They found inconsistent care in relation to:

- Assessment of care needs being addressed
- Providers working together and Information sharing
- Service users and carers involvement in decision-making
- Planning, delivery of care and personalisation
- Staff training and knowledge of dementia
- Monitoring systems to routinely check quality of care

In 2015, The Prime Minister's Challenge on Dementia 2020 was set up and has since been recommitted to by the current government. The challenge outlines several commitments for dementia care, support and research with the aim to become "the best country in the world for people with dementia, their carers and families to live"[3].

The NHS Long Term Plan (2019) has also set out to improve support and care for people experiencing organic mental health needs by committing to "go further in improving the

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[1] Alzheimer's Society (2015) www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia_2015_aiming_higher_to_transform_lives.pdf

[2] CQC (2014) www.cqc.org.uk/sites/default/files/20141009_cracks_in_the_pathway_final_0.pdf

[3] Department for Health (2015) www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020

care we provide to people with dementia and delirium, whether they are in hospital or at home”.

The National Institute of Health and Care Excellence (NICE) published guidance for assessment, management and support for people living with dementia and their carers (NG97) in June 2018.

It is important to note that dementia does not only affect people who are 65 and over. Young onset dementia affects an estimated 44,000 people in the UK and on average can take twice as long to diagnose than dementia experienced by older people[4].

## 3. Local Context

Within North Tyneside, the proportion of people aged 65 and over stands at 20% which is higher than the national average of 18% and is expected to grow. We also have approximately 2,800 people living with dementia and this number is expected to rise to approximately 3,861 by 2025.

North Tyneside Clinical Commissioning Group (CCG) has outlined a number of commissioning priorities (2018/2019) which aim to improve mental wellbeing for older people in the borough. North Tyneside Council and North Tyneside CCG have also developed the Mental Wellbeing in Later Life Strategy (2018-2023) with the intention to improve mental health and dementia services. They have emphasised prevention and early intervention as key areas of focus.

Two NHS Foundation Trusts are involved in the provision of Mental Health Services for older people in North Tyneside: Northumbria Healthcare NHS Foundation Trust and Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust (CNTW). The majority of service provision is delivered by Northumbria and CNTW provide services for people living in the North West of the borough.

## 4. What we did

Between August 2019 and January 2020 we spoke to 61 people about their experiences of memory and dementia services for older people. We gathered their feedback through both one-to-one interviews and group discussions. Participants included 26 service-users, 34 carers and/or family members and one paid carer/care home staff.

We have also received feedback through our general engagement activity from nine people and spoke with a range of stakeholders and staff about their experiences of working within these services.

We spoke with people from various parts of the borough, however, we only heard from a limited number of people living in the North West. This is likely to mean that the majority of feedback we received related to services provided by Northumbria Healthcare NHS Foundation Trust.

For full demographic information about who we spoke to see Appendix 1.

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[4] NHS (2017) www.england.nhs.uk/blog/tackling-the-challenges-of-young-onset-dementia/

Full information has been shared with members of North Tyneside's Mental Wellbeing in Later Life Board who have helped shaped the recommended actions and reviewed drafts of this report.

## 5. Key Findings

Our key findings, alongside appropriate guidelines for good practice, are outlined below.

### 5.1 Identification, Referrals and Diagnosis

The Prime Minister's challenge on dementia 2020 states that one of their key aspirations for 2020 is:

"In every part of the country people with dementia having equal access to diagnosis as for other conditions, with an expectation that the national average for an initial assessment should be six weeks following a referral from a GP (where clinically appropriate), and that no one should be waiting several months for an initial assessment of dementia"

#### Identification

GPs are the first step to getting a diagnosis.

People told us that they often experienced long waits for referral to a memory clinic for a diagnosis due to GPs not efficiently spotting the signs of dementia. People told us that some GPs conduct a short memory test and some people told us they felt the test used only looks at memory and does not reflect any changes to behavior. Some people described a prolonged identification process with their GP "going back with the same issue over 2-3 years before GP made the referral to the memory service." This made people feel that some GPs did not have the specialist knowledge or ability to identify issues early.

"Signs of dementia 2 years earlier but no diagnosis"

"Person told us that they initially went to their GP when they couldn't write and it was put down to bereavement – person said they had to push for the GP to refer them to the memory clinic"

During discussion of this report in draft with the Mental Wellbeing in Later Life Board, it was suggested the following additional action be added to this report.

**ACTION: Review the approach to early cognitive decline and pre-diagnosis of dementia to include monitoring and reviewing through primary care and memory assessment services as well as information for services users, families and carers. This could include better links and awareness between GPs and Admiral Nurses.**

### Referral to memory clinic

People did tell us that once the referral had been made to a memory clinic, the assessment at the memory clinic speedily followed. We heard generally positive experiences of diagnosis; one carer described it as “speedy, relevant, appropriate”. However, diagnosis for conditions like vascular dementia due to stroke weren’t as quickly identified.

> “Person has never had a dementia diagnosis even though experiencing dementia since they had a stroke. Feels there is no real acknowledgement of vascular dementia”

### A holistic view

We also heard from family and carers about experiences of the person with memory issues often downplaying, denying or masking their issues to medical staff. This meant that diagnosis or changes to their condition may not be accurately presented to staff and lead to difficulties when accessing appropriate services and support.

Family and carers also told us that they sometimes felt that their insights were not taken on board by medical professionals. This made it difficult for people to get support early and adds pressure on family, but also highlights the impacts of confidentiality issues. This was highlighted as an area of concern throughout people’s experiences as one person explained that their views as a carer were not taken on board during continuing care assessments.

> “There was a difficulty during diagnosis as carer’s mother would tell professionals that everything was fine and carer was then trying to be honest with the professionals whilst also worrying about their loyalty to their mother”

**NICE Guideline 1.2.1** says the starting point for any:

> ‘initial assessment involves taking a history (including cognitive, behavioral
> psychological symptoms, and the impact symptoms have on daily life):
>
> - From the person with suspected dementia **and**
> - If possible, from someone who knows the person well (such as a family member’
>
> NICE’s emphasis.

From what we have heard, the NICE Guideline 1.2.1 is not always being met.

**ACTION: the CCG should work with councils of practice to ensure this guideline is delivered consistently.**

### 5.2 Immediately following diagnosis

As part of this research and in other work we have done, the importance of high-quality information and support immediately following diagnosis is highlighted.

We wanted to know what services and support people used once they had received a diagnosis. People told us about their experiences of using a number of services, what worked and what could have improved their experience.

Initially, this information comes from the memory clinics. People were very positive about their experiences at the memory clinic they attended. The vast majority of people we spoke to either talked directly about the service Northumbria Healthcare NHS FT provide or we can assume they were referring to this service based on geography.

> “They were excellent”
>
> “All very good, do tests where they ask questions and then stayed for a course of support”
>
> “Everything they’ve said or done has been great”

People found the follow up sessions provided by the Memory Clinic helpful but some commented that the time-limited nature of these wasn’t enough; one person told us that they were “quite helpful, but not long enough”.

Following diagnosis, the main issue that patients, carers and family told us about was the lack of information and support available and signposted to. Several people told us they felt left with no information and limited support after discharge from the memory clinic. One person explained that when the memory clinic sessions ended “it felt like you drop off the edge of a cliff”.

Section 1.1.6 and 1.1.7 of the NICE guidelines set out the expectations for information immediately after diagnosis, including information about local support groups. From what people told us, this standard is either not being met, or the information provided is inadequate or poorly communicated so that people cannot make best use of the information given. There are also guidelines for provision of information for family and carers.

**ACTION: Review the information provided to people with a new diagnosis of dementia and test with users about what would be the best way to share information effectively.**

### 5.3 Support

People told us that they found the Admiral Nursing service “invaluable”. It emerged that not everyone had access to the Admiral Nurse service or knew it existed and people were unclear why some had received and benefited from the Admiral Nurse service and others had not.

**ACTION: Clarify the criteria and access routes to the Admiral Nurse service and ensure these are clearly communicated to people.**

Support groups within the community were highly praised; in particular people discussed the peer groups ran through AGE UK, Silverline Memories, the Carers Centre and the Making Waves group.

> "Was introduced by friend to AGE UK and couldn't appreciate it any more, everyone friendly, everyone the same, not embarrassed. AGE UK worker visits and helps keep son updated too – nothing is too much of a problem"
>
> "Person felt some groups sometimes talked like they were children whereas this one [making waves] was good as they didn't do that"
>
> "It [making waves] was very good as there was time to be together but also time separated so carers could spend time together"

The support groups people attended were often an integral part of the care and support received, for people experiencing dementia and their carers and families. They also played a vital role in providing information and signposting.

Awareness of what support was available was often low until a person joined a support group, meaning people often only heard about the support groups through word of mouth.

> "Didn't really get any info before coming to AGE UK group. They told us about things like council tax exemption"
>
> "AGE UK staff member visited house and brought lots of information and leaflets so they could see what support was available"

It appears there is a significant gap in provision: local easy-to-access and up-to-date information about support groups and other information that would be useful for people to know (benefits, carers support etc.).

**ACTION: Review the provision of support groups across North Tyneside. Public sector providers should support these groups to fill gaps and be sustainable parts of the dementia service provision, recognising the importance these groups have in reducing loneliness, supporting carers and providing information.**

**ACTION: Produce easy to use and easy to access information for people with dementia, their family and carers that can be accessed at any point following a diagnosis and is regularly updated. The Mental health support leaflet could be a model for part of this alongside information available through the SiGN network.**

Another key barrier to accessing support for several people was the lack of transport options to get to a support group and the financial cost of attending the groups which incurred a cost. Some people told us that transport options were either unaffordable or inappropriate for the person's needs. Section 1.3.6 of the NICE Guidelines sets an expectation that services providers design services that are as accessible as possible.
**ACTION: Review transport needs for users of services and identify ways to meet unmet needs.**

## 5.4 Role of GP

Although GPs are a key step in the process of accessing specialist support, once referral has taken place people told us that some people had very little contact with their GP about their continuing health and care needs. Many people praised their experiences of interacting with their GP and often commented positively on the staff approach, but some were criticized for a perceived lack of knowledge and understanding. The majority of people we heard from told us that they did not often see their GP.

> “The GP had very little involvement”
>
> “Never really go much”
>
> “Person told us that they haven’t been to their GP as it’s so busy they don’t think they would get an appointment”

## 5.5 Care coordination

**NICE Guidelines 1.3 Care Coordination**
1.3.1 Provide people living with dementia with a single named health or social care professional who is responsible for coordinating their care.

1.3.2 Named professionals should:

- arrange an initial assessment of the person's needs, which should be face to face if possible
- provide information about available services and how to access them
- involve the person's family members or carers (as appropriate) in support and decision-making
- give special consideration to the views of people who do not have capacity to make decisions about their care, in line with the principles of the Mental Capacity Act 2005
- ensure that people are aware of their rights to and the availability of local advocacy services, and if appropriate to the immediate situation an independent mental capacity advocate
- develop a care and support plan, and:
    - agree and review it with the involvement of the person, their family members or carers (as appropriate) and relevant professionals
    - specify in the plan when and how often it will be reviewed
    - evaluate and record progress towards the objectives at each review
    - ensure it covers the management of any comorbidities
    - provide a copy of the plan to the person and their family members or carers (as appropriate).

Section 1.3 of the NICE Guidelines sets out that every person should have a **named care coordinator** and the role of that person. Feedback from users and carers indicates that people remain unclear who their care coordinator is.

During the assessment and diagnosis phase, it appears that some elements of the care coordinator role is being delivered by a GP and the memory clinic. Later, this might be done by an Admiral Nurse, care worker or social worker. However, the experience does not appear consistent, and there are key aspects that seem to be missing for example, nobody we spoke to talked about a *care and support plan,* other than the social care support package they may receive.

The Prime Minister's challenge on dementia 2020 states that one of their key aspirations for 2020 is:

"GPs playing a leading role in ensuring coordination and continuity of care for people with dementia, as part of the existing commitment that from 1 April 2015 everyone have access to a named GP with overall responsibility and oversight for their care".

People did tell us about feeling 'left to get on with it' and being unclear who to go to for advice or if someone's needs changed. People do not see their GP as their named care coordinator. If the GP is to be their named coordinator then service users and GPs need to be clear about this and should consider how best to meet the NICE guidelines.

**ACTION: Review current arrangements for named care coordinators in North Tyneside and take action to ensure that the NICE guidelines are being delivered and it is clear how support and care plans will be reviewed.**

### 5.6 Changing needs and reviews

We heard mixed experiences about people getting professional advice as their condition deteriorates. People told us that when they were discharged from the memory clinic, they needed to go to their GP to be referred back to the memory clinic, unless they have maintained a relationship with the memory clinic. From our information, it is not clear when someone would be fully discharged from a memory clinic. The process for re-referral back into the service, via their GP, raised some concerns from users about the efficiency of this approach and the knowledge of the GP.

**ACTION – Clarify the pathways for ongoing support and review process (including considering periodic reviews) and provide clear information to users and carers.**

### 5.7 Advance Care Planning

NICE guideline 1.1.12 set out people should be supported to plan for their future lead by their named care coordinator. This was not mentioned in any of the interviews we conducted. Family and carers did highlight how important this advance care planning is and that more information and support, early in the diagnosis, would have been helpful.

**ACTION: Review how advance care planning is currently discussed with every person.**

### 5.8 Support to live at home

The majority of people we spoke with felt that they had limited interaction with statutory adult social care services. We were surprised by this but may reflect that a significant number of people are supporting themselves within the family or that people are not aware of the support they receive.

North Tyneside Council's Adaptations and Loan Equipment Service was universally rated very highly.

People who had had contact with a social worker said that their main activity was often just received visits to set up a care package.

Some carers have raised concerns about difficulty in arranging high quality care at home and Healthwatch North Tyneside will gather further information about this separately.

> "As person was self-funded in care home they had minimal interaction with Local Authority Social Care"

### Care package changing whilst in hospital

Whilst being in hospital and upon discharge, people felt that there was a lack of communication between services. One person said that the persons care package was terminated due to being in hospital. Another noted the time of discharge often made the process of moving back to their care home a challenge – "discharged from hospital in a rush at 8:30pm".

**ACTION: Healthwatch North Tyneside to gather further information about experiences of arranging and receiving care at home.**

### 5.9 Living in a Care Home

A number of people discussed positive experiences of the care received by their care or nursing home.

> "The care home was brilliant, staff 'knew' the person so felt comfortable that they would provide good care and work with persons preferences and likes in mind"

However, there were also areas for improvement. People often commented that care homes were understaffed and had limited time to support the residents fully. This meant that carers felt that they sometimes had to advocate or remind staff about aspects such as providing regular showers or the person's preferences. Some carers felt comfortable doing so but others also worried incase this impacted on the care their loved one received.

“My mum has been a resident at [care home] for two years and is cared for very well. However, I do have to remind them she needs a shower or her hair washed but she seems happy and content”

“Staff tried their best but too few of them and not well trained”

“Care homes run medical model and tend to manage people rather than helping them thrive”

## 5.10 Hospital Care (for non-dementia related issues)

The Prime Minister’s challenge on dementia 2020 states that one of their key aspirations for 2020 is:

“All hospitals and care homes meeting agreed criteria to becoming a dementia friendly health and care setting”.

People told us about various experiences of using health services for non-dementia related conditions and issues. Most people felt that hospital treatment was poor due to lack of awareness and knowledge about the needs of someone with dementia. This was particularly noted by carers who shared experiences of staff being unable to address needs of people who are unable to communicate. Generally, hospital wards were not seen as an appropriate place for people with dementia to stay. This is a common issue we hear from people who have additional needs when staying in a hospital setting.

“Once went in for chest pain and carer visited to find person cold and alone, doing nothing with the window open and not given food even though they were diabetic”

“Consultant didn’t understand dementia and person came out confused due to far too many technical words”

“In hospital they’re dependent on the carer to manage all the communication. My husband couldn’t speak, the assessor for the Continuing Health Care budget saw him on her own, and she told me “I’ve had a pleasant conversation with your husband”

Carers told us that they invariably had to spend a lot of time at the hospital as staff were often too busy to deal with their relative’s needs. Others felt that the standard visiting times were too short when visiting their relative with dementia.

The main issue people raised when considering their experiences of hospital care was the lack of staff awareness and skills to support people with additional communication needs. This meant again that carers felt pressure to advocate for the patient or worry that they were not having their needs adequately met. We were told about medication (see 5.12) and security guards being used to manage dementia behavior in a general healthcare setting.

Section 1.13 of the NICE Guidelines sets out expectations for training for health and care staff.

**ACTION: Review how best to support people with dementia in general healthcare settings. Consider taking lessons from other groups that have additional support needs – e.g. people with learning disabilities.**

**ACTION: Review how best people's support needs can be communicated with services so that appropriate action can be taken – e.g. wellbeing passport.**

### 5.12 The Use of Medication

NICE guideline [NG97] section 1.7.3 states that services should:

"Only offer antipsychotics for people living with dementia who are either:

- at risk of harming themselves or others **or**
- experiencing agitation, hallucinations or delusions that are causing them severe distress"

The appropriate use of medication was discussed in relation to both those living in care homes and when people were admitted to hospital. Carers often felt that anti-psychotic medication was overused to help staff to deal with "challenging behavior".

> "Agreement in group [of carers] that anti-psychotic drugs are overused, especially in crisis…the person is given drugs to manage behavior…If someone has an infection and is in a medical ward they give anti-psychotic's to stop them wandering"

### 5.13 Referrals to the Mental Health Team

The main issue carers and staff described was the difficulty in meeting the requirements to make a referral into the older people's mental health team – this included a urine sample and blood sample which was often impossible to retrieve from service-users. This led to frustrations with both families and care home staff who had to struggle to meet these requirements and do so quickly when a person's mental health is deteriorating. In some instances, care home staff would ask family members and carers to try and help to get such samples which could compromise the dignity of the patient and carer.

Similarly to during the diagnosis process, some medical staff and carers also felt like their experience of supporting the person was not listened to during the process.

> "Person felt that Community Psychiatric Nurse's often didn't listen to care home staff and only listened to the care home manager even though the care staff support residents on a daily basis and know changes in their behavior best"

## 6. Carers

### 6.1 Carer’s role and needs

We wanted to hear from carers about their experiences of support as a carer, as well as their views of dementia serices. We heard positive experiences of carers feeling like partners in care - “me and the care home are in partnership” - and poor experiences of carers’ views and experiences being ignored by professionals. This meant that sometimes the carers’ fear of making things worse acted as a barrier to advocating and navigating services.

> “You need a will of steel to navigate health and social care services – even the most robust of us will quiver at the worry of making things worse”

Carers discussed having limited time to support their own wellbeing. This was both when the person they cared for lived at home and when they were residents at a care home. One person noted that they felt the same level of responsibility for their relative when they were moved into a care home but just less control – “forever on alert”. Another person told us that 85%-95% of the time they didn’t feel like a partner in care by other services.

As noted above, access to information and support was a key issue both at the point of diagnosis, discharge from the memory clinic and from other services such as their GP. This includes information about what support groups are available (most people hear through word of mouth or by chance), information about financial support, hospital passports and blue badges. Carers who had accessed support from North Tyneside Carers’ Centre were positive about this, particularly the courses, however only a small percentage had accessed support from the Carers’ Centre and many were not aware of the support available.

Carers’ experiences of being offered support for their own wellbeing and their role as a carer were similarly inconsistent. Only one person we spoke to noted being offered signposting and advice about both their relatives’ needs and their own as a carer by services. Some people had small levels of information provided but this was largely inconsistent and limited post-diagnosis. From the carers we heard from, only two people mentioned that they were offered a carers assessment. The majority of people had not been offered and some could not remember if they had been offered one, illustrating both low awareness and uptake by carers.

**ACTION: When developing information and providing information to service users, ensure information about support for families and carers is also highlighted.**

**ACTION: Health and care providers improve ways to identify carers and the changing needs of carers over time.**

**ACTION: Health and care providers provide carers with information about their rights and the support available, particularly the right to a carers assessment.**

**ACTION: Health and care providers talk to carers about their role and expectations of them whilst the person they care for is receiving care.**

### 6.2 Crisis Planning

A key concern for carers was around crisis planning which was often not discussed or given information on by health and care professionals. This was both in relation to people with dementia having a crisis point where things get significantly worse and also when carers ended up being ill or unavailable with no plan in place to support the person they care for.

Similarly, people often felt that a care situation needed to reach a crisis point before any help or support was available to them. This was particularly challenging as the availability of respite was described as limited and people told us that it often needed to be booked in advance so was not available for urgent cases.

**ACTION: Health and care providers provide information to carers about what to do if a crisis occurs.**

**ACTION: Health and Care providers and commissioners consider taking action earlier to prevent a situation reaching crisis.**

## 7. Acknowledgements and Next Steps

We would like to thank all of the orgainsations that helped us conduct our research: particularly:

- Silverline Memories
- Age UK North Tyneside
- North Tyneside Carers' Centre
- Northumbria Healthcare NHS Foundation Trust
- North Tyneside Council

We have worked closely with North Tyneside's Mental Wellbeing in Later Life Board who have helped shaped the recommended actions and reviewed drafts of this report. The Board is using this report to develop an action plan to review and improve services and some actions are already underway.

Finally, we would like to thank all of the residents of North Tyneside who took the time to share their experiences and help to improve services for everyone.

## 8. List of Suggested Actions

Below is the list of actions identified by this project based on local people's views and feedback:

### 5.1 Identification and referrals

Review the approach to early cognitive decline and pre-diagnosis of dementia to include monitoring and reviewing through primary care and memory assessment services as well as information for service users, families and carers. This could include better links and awareness between GPs and Admiral Nurses. (page 3)

### Holistic/family view

The CCG should work with councils of practice to ensure the NICE guideline 1.2.1 is delivered consistently. (page 4)

### 5.2 Immediately following diagnosis

Review the information provided to people with a new diagnosis of dementia and test with users about what would be the best way to share information effectively. (page 5)

### 5.3 Support

Clarify the criteria and access routes to the Admiral Nurse service and ensure these are clearly communicated to people. (page 5)

Review the provision of support groups across North Tyneside. Public sector providers should support these groups to fill gaps and be sustainable parts of the dementia service provision, recognising the importance these groups have in reducing loneliness, supporting carers and providing information. (page 6)

Produce easy-to-use and easy-to-access information for people with dementia, their family and carers that can be accessed at any point following a diagnosis and is regularly updated. The Mental Health Support leaflet could be a model for part of this alongside information available through the SiGN network. (page 6)

Review transport needs for users of services and identify ways to meet unmet needs. (page 7)

### 5.5 Care coordination

Review current arrangements for named care coordinators in North Tyneside. Take action to ensure that the NICE guidelines for care coordination are being delivered and it is clear how support and care plans will be reviewed. (page 8)

### 5.6 Changing needs

Clarify the pathways for ongoing support and review process (including considering periodic reviews) and provide clear information to users and carers. (page 8)

### 5.7 Advance care planning

Review how advance care planning is currently discussed with every person. (page 8)

### 5.8 Support to live at home

Healthwatch North Tyneside to gather further information about experiences of arranging and receiving care at home. (page 9)

### 5.10 Care whilst in hospital for on- dementia related issues

Review how best to support people with dementia in general healthcare settings. Consider taking lessons from other groups that have additional support needs – e.g. people with learning disabilities. (page 11)

Review how best people’s support needs can be communicated with services so that appropriate action can be taken – e.g. wellbeing passport. (page 11)

### 6.1 Carers role

When developing information and providing information to service users, ensure information about support for families and carers is also highlighted. (page 12)

Health and care providers improve ways to identify carers and the changing needs of carers over time. (page 12)

Health and care providers provide carers with information about their rights and the support available, particularly the right to a carers assessment. (page 12)

Health and care providers talk to carers about their role and expectations of them whilst the person they care for is receiving care. (page 12)

### 6.2 Crisis planning

Health and care providers provide information to carers about what to do if a crisis occurs. (page 13)

Health and Care providers and commissioners consider taking action earlier to prevent a situation reaching crisis. (page 13)

## Appendix 1

### Who we spoke to

It is important to note that not everyone we spoke to chose to provide demographic information about themselves, some provided full details and others only provided partial information.

### Location (First part of postcode)

The majority of those we heard from were from the East of the borough. A minority of people lived outside of North Tyneside but they often cared for a person living in North Tyneside.

Map illustrates spread of postcodes not prevalence.

### Other demographics

There was a significantly higher response rate from females, with 34 females and 15 males sharing feedback. The age of those people we spoke to ranged from 22 years old to 91 years old, however, the majority of people were over 60 years old. Everyone we spoke to identified their ethnicity as White British.

Of those who responded, 19 people identified as a carer and 8 identified themselves as being disabled.