

## **Lincolnshire Joint Commissioning Strategy for Dementia Care 2014 – 2017: The Way Forward**

### **Consultation Evaluation Report**

1

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# Adult Care

## Table of Contents

1. Information and Background	3
2. Executive Summary – What Matters to People with Dementia, their Families and Carers	4
3. Methodology	6
4. Profile of Consultation Respondents	8
5. Key Themes and Findings from the Lincolnshire Joint Strategy for Dementia 2010 – 2014 Refresh	12
a. Themes	13
b. Findings	19
6. Early Onset Group Analysis	24
7. Acknowledgements	25
8. Appendices	
a) Sample Responses and Data from Lincolnshire Joint Strategy for Dementia 2010 – 2014 Online Consultation Questionnaire	26
b) Responses from LPFT/Carers/Lincolnshire Residents Groups	56

2

## Information and Background

In March 2013, The Shadow Health and Wellbeing Board for Lincolnshire agreed to refresh of the Lincolnshire Joint Commissioning Strategy for Dementia Care 2010 -2014. Dementia presents a growing challenge as our population ages. Projections for the period 2008 - 2023 show a doubling of cases in most area of Lincolnshire.

The existing Lincolnshire Joint Strategy for Dementia Care was launched in 2010 and many people and organisations have been working creatively within a difficult economic climate to deliver changes over this period

The current strategy is due to expire March 2014. Social care and NHS commissioners propose to refresh the existing strategy and determine future strategic options.

Plans to develop and improve dementia services are already in progress. Department of Health funding made available through NHS Lincolnshire is being used to support a number of initiatives consistent with national and local priorities.

Health and social care partners in Lincolnshire are focusing on the key areas outlined in the Prime Minister's Challenge on Dementia (2012):

1. Creating dementia friendly communities
2. Driving improvements in health and care
3. Delivering the National Carers' Strategy for dementia carers

A consultation programme to inform the strategy refresh process opened on 20 May and closed on 19 July.

The consultation has been necessary to evaluate progress and for everyone to be able to share and understand both what has been achieved to date and what remains to be achieved.

There will be ideas from the current strategy that still need action, can no longer be delivered, or should be delivered in a different way. The aim of this consultation report is to help inform a new strategy and action plan as well as validating current work; it is important that as many individuals and organisations as possible have the opportunity to contribute their ideas, suggestions and views to this process.

3

## Executive Summary

### What Matters to People with Dementia and their Families

In order to best serve the people of Lincolnshire in the arena of dementia, it was vital that the views of the residents of Lincolnshire, particularly those with a direct interest in people with dementia be given a voice. That was the aim of launching the dementia consultation in May 2013.

The nature of the consultation left much scope for the people responding to make comments and suggestions about their own experiences and also their ideas for improvements to the way care is administered to people with dementia, their families and carers in Lincolnshire. Many of the respondents seized this opportunity to let us know what their views were and we trust that this report has highlighted and represented their views to assist in the drafting of the Lincolnshire Joint Commissioning Strategy for Dementia Care 2014 – 2017.

After analysis of the comments and answers received, key themes emerged as to what respondents valued most in relation to dementia and dementia care as highlighted in the appropriate section of this evaluation report.

4

The key conclusions to be drawn from the data that has emerged are: -

#### **Better Information**

This includes: -

- Knowledge about dementia and its potential effects
- Knowledge of what help and advice is available
- Publicity to be made available to the general population so as to increase understanding of dementia and its effect upon the behaviour of those with the condition.
- Knowledge amongst health and social care professionals and staff about how to treat people with dementia.

# Adult Care

## **Better Services**

This includes: -

Good quality care and support services to allow people to stay in their homes for longer  
Access to available residential respite care, day care and sitting services to allow carers to have a break to support them in their vital role as unpaid carer.  
Community based support groups and activities to increase activity and wellbeing and reduce social isolation.

Making the system user friendly, providing seamless services across health and social care with a clear pathway to make navigating the system less daunting.

## **Making Communities Dementia Friendly**

This includes: -

Dementia friendly environments in hospitals, residential care homes and at home.  
Information on home adaptations  
Shops, banks and businesses to be more aware, and amenable to assisting families dealing with dementia issues.

5

## **Recognition, Dignity, Respect and Consultation**

This includes: -

Allowing families of people with dementia, and their carers to be included in making decisions about the treatment and care of people with dementia.  
Giving due recognition and respect to those providing unpaid care.  
Ensuring people with dementia and their families are always treated with dignity, compassion and respect.

There were many responses that suggested that health and social care are already making positive strides to achieve the desires of people with dementia, their families and carers in Lincolnshire, but clearly there is much work to be done in order to try to meet their needs and expectations over the course of the next Lincolnshire Joint Commissioning Strategy for Dementia Care.

# Adult Care

## Methodology

An online questionnaire formed the main basis of the consultation and was drafted with assistance from a range of stakeholder and user groups throughout Lincolnshire, and was primarily led by Lincolnshire County Council's Public Health department.

The following organisation's views were sought: -

Age UK

Alzheimer's Society

Boultham Park House Memory Café

Dementia Support South Lincs

East Lincolnshire District Council

Healthwatch

Lincolnshire Carers' and Young Carers' Partnership

Lincolnshire Community Health Services NHS Trust

Lincolnshire County Council Adult Care

Lincolnshire County Council Public Health

Lincolnshire Partnership NHS Foundation Trust

South West Lincolnshire Clinical Commissioning Group

Square Hole group

St Barnabas Hospice

The questionnaire was promoted and made available through dedicated information webpages on the Lincolnshire County Council website.

A hard copy paper version of the questionnaire and an easy read version of the questionnaire were also made available on request.

6

# Adult Care

Regular information about the consultation was cascaded to all Lincolnshire County Council staff via the Communications Team, who also issued a press release in order to publish information about the consultation to the general public, and regular updates and reminders were also sent out via the Lincolnshire County Council twitter account throughout the duration of the consultation period.

Hard copies of the consultation questionnaire were also made available at various events held in Lincolnshire, including the Lincolnshire Show.

Details about the consultation for the strategy was added to the Lincolnshire County Council corporate consultation calendar, which the public can view to see what consultations are taking place and what policies and developments they can influence.

There were also facilitation groups set up to gather some group responses to the consultation (See early onset group and groups mentioned in the profile of respondents)

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## Profile of Consultation Respondents

A total of 91 online questionnaires were received during the consultation period from individuals. Incorporated into the online survey were also several group responses which were facilitated by a leading dementia charity in Lincolnshire. There were a further 68 responses which were received in hard copy format of an earlier version of the consultation which differed in format to the online questionnaire. These responses are captured separately in the section entitled: - Responses from LPFT/Carers/Lincolnshire Residents Groups and are broken down as follows: - 44 health and social care professionals, 5 carers and service users, 19 Lincolnshire residents.

There was also a group of people of working age who had been diagnosed in the early stages of dementia. The responses of this group were captured in the section marked: - Early Onset Group Analysis.

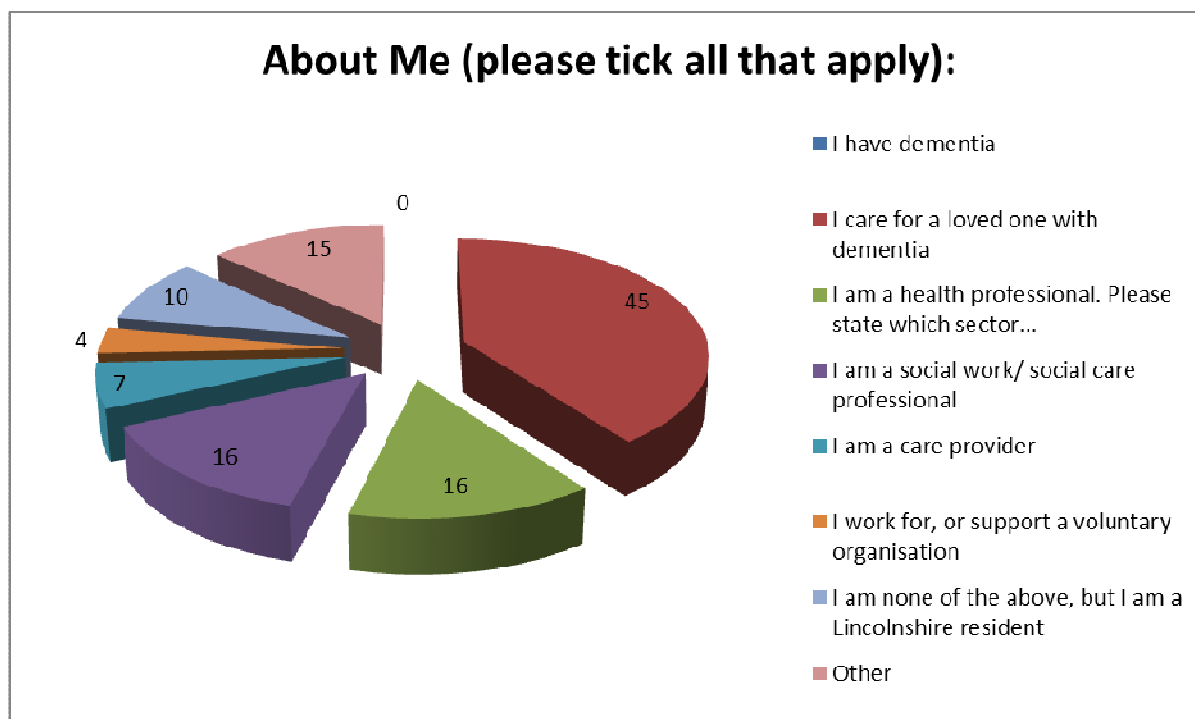
Demographic data exists only for the 91 people who were included in the individual responses to the online questionnaire which includes age, gender, ethnicity, religion, sexual orientation, whether they have a disability, stage of the dementia journey they are at and their role i.e. – carer, social work professional etc.

The breakdown is shown below: -

8



# Adult Care



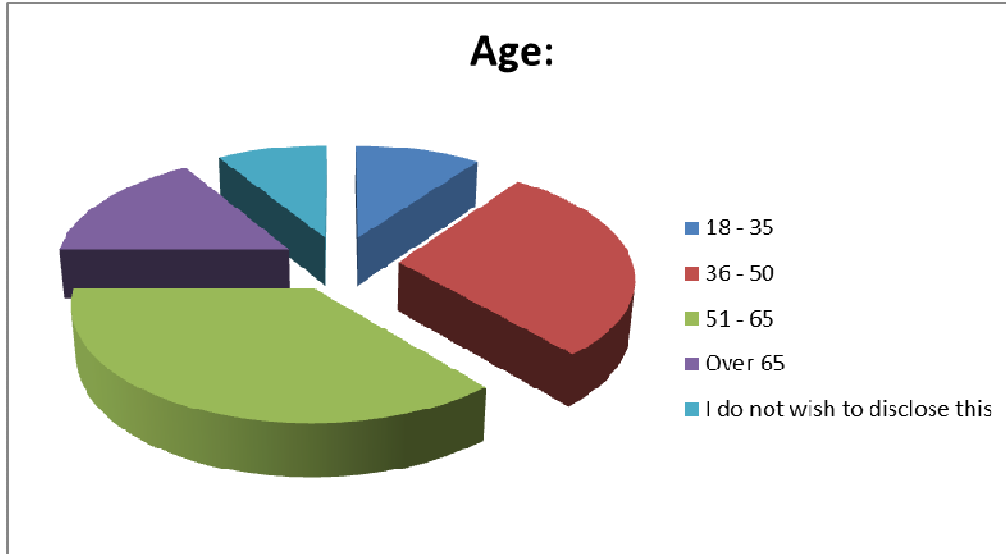
9

It should be noted that respondents were able to tick more than one category. The largest group of people were those who classed themselves as carers. Carers play a huge role within the United Kingdom and it is particularly welcome that they are well represented within this consultation.

A significantly larger proportion of females 76.9% completed the questionnaire, 18 of those who responded to the gender question being male which accounts for 23.1% of the total participants. A total of 13 people chose not to respond to this question.

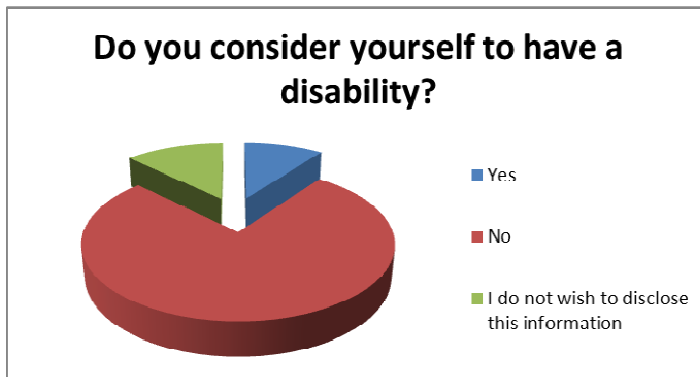
# Adult Care

The ages of the respondents is illustrated as below: -



The most well represented groups were 51 – 65 (36.3%) and 36 – 50 (28.8%) representing 65.1% of the total respondents

10



10 % of respondents considered themselves to have a disability, 12.7% stating that they did not wish to disclose this

The "typical" respondent to the questionnaire then was a white, heterosexual female between the ages of 36 and 65. With one exception, all of the respondents to the survey were Christian, atheist, no religion or did not wish to disclose this. The only exception being one person who stated their religion as Judaism.

# Adult Care

Likewise, there were only 3 people who stated their ethnicity as anything other than white or do not wish to disclose.

There was a good spread of people across Lincolnshire with most areas of the county being represented in the survey.

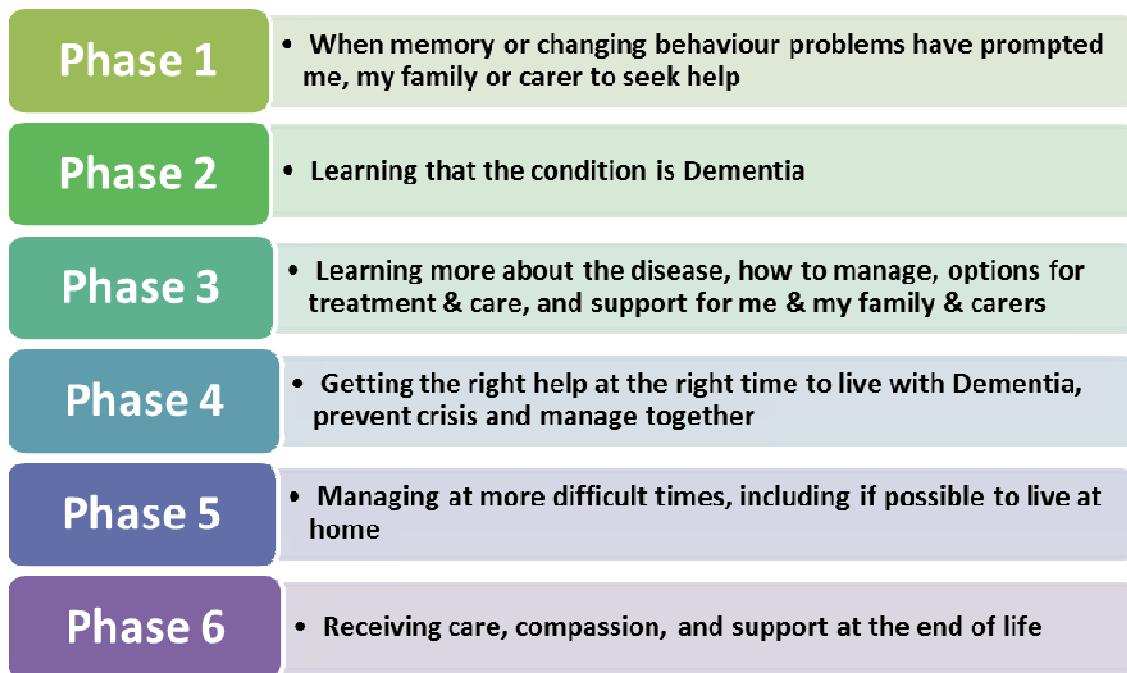
## **Conclusion**

There were a total of 159 individual responses, plus several group responses. There were a wide range of opinions and suggestions made which was encouraging. There may be lessons to be learned in the approach that was taken. There was no section asking about the user's experience of completing the online questionnaire. There were some comments made about its length which may be worth considering in the future.

People with dementia were represented by the 22 people in the "Early Onset Group. The experiences of family, carers and people within the health and social care arenas were well represented.

# Adult Care

## Key Themes and Findings from the Lincolnshire Joint Strategy for Dementia 2010 – 2014 Refresh



12

The consultation questionnaire was grouped into 6 broad areas which follow the "Dementia Journey" (see above) from seeking help when the first signs of dementia start to show themselves, through learning and planning for the future, living well with dementia and right through to the end of life.

The consultation questionnaire was geared towards allowing respondents to tell us about their experiences, suggestions as to what would or could help them as they progress through the dementia journey, and to tell us what is important to them. Whilst analysing the information in the consultation, key themes have emerged, particularly from this narrative thread.

The quantitative data is dealt with mostly in the sections concerned with each stage of the dementia journey; this section will look at the themes that are emerging from what people have been telling us in their responses.

The key themes will mirror, but not follow exactly, the dementia journey as it has done throughout the consultation questionnaire. The best way to illustrate the key themes is to give show what our respondents have had to say about the various topics listed

# Adult Care

## Themes

### Phase 1

- When memory or changing behaviour problems have prompted me, my family or carer to seek help

#### Early diagnosis of dementia and knowledge about the disease and how it affects people

*"Forget attitudes, it has taken two years for my father to be diagnosed. An initial visit to his GP resulted in no action. He was eventually referred to the Psychiatrist at Fen Lane? who turned up not notifying them of an appointment. The next appointment he did not keep and he finally kept the third appointment nearly a year after my father was referred. Then he had a scan and waited two months for referral back to Fen Lane. My father has deteriorated considerably in this time. What a useless service! I can only assume that there is not enough provision for diagnosis initially."*

*"Intervention as soon as diagnosis is confirmed to include family members/support/carers to explain what help is available."*

*"Being given information about the condition and likely progression at the time of diagnosis. I had to find this out for myself."*

13

*"More information on the way the dementia may progress."*

*"Face-to-face professional contact - to gain understanding and put things in perspective."*

### Phase 3

- Learning more about the disease, how to manage, options for treatment & care, and support for me & my family & carers

#### Publicity for the general public about dementia and how it affects people

*"Raising awareness with the general public through a PR and public education campaign."*

*"Raise awareness of what people with dementia are capable of - at some stages they can be re-abled in some aspects of their lives."*

*"Public awareness to help with embarrassment when out in the community."*

# Adult Care

*"A change in public opinions towards family carers - it is a positive and worthwhile experience, yes it can be stressful, but it is generally only seen in a very negative light."*

*"The general public are becoming more aware of dementia and what this means because it is spoken about more but there are still so many misconceptions."*

*"Educate and inform the public, get rid of many of the false ideas people have about dementia and dementia services. Promote how to spot the signs and symptoms so people can get help early."*

*"There's a lot of scaremongering about dementia. Whilst it's true that there isn't a cure there's an attitude that once someone has dementia then life is over. This simply isn't true and again there needs to be a great deal more publicity to get this across."*

## Phase 4

- Getting the right help at the right time to live with Dementia, prevent crisis and manage together

### Giving the carer a break including access to respite care

14

*"Respite care to give carers a break or so they can do simple tasks such as the shopping."*

*"Sitting Service or buddy service in the early stages where for example someone who likes gardening could have come to the house and helped Dad in the garden as he forgot how to do things, when to set things etc or how to carry on making his wine. It would have helped home to continue to feel useful."*

*"Access to pre-planned, guaranteed, bookable Respite Care. This is THE issue for me."*

*"More respite care that can be relied upon to be available when necessary - sometimes planned other times needed for crisis."*

*"Working full time while caring for my husband I needed to plan respite breaks in advance. Local homes do not necessarily have beds that can be booked ahead. I was also fortunate to have a support group that offered social activities and support for me and my husband when he was able to participate. This doesn't happen across the whole of the county."*

### Community based services and support groups

*"Adequate clubs and social events for people with dementia and family/cares."*

# Adult Care

*"Services which enables the person to continue with community independent living."*

*"Opportunities to participate in community & daily activities that provide stimulation, enjoyment and help to enrich life - provided with dignity and respect."*

## **Making communities and environments dementia friendly**

*"Dementia friendly environments in hospitals and homes."*

*"Information on home adaptation e.g. contrasting colours, labels on drawers / cupboards."*

*"Shops/businesses/services being more 'dementia friendly'."*

*"Helpful environment - lockable cupboards help with understanding what is happening."*

## **Availability of good quality support and services.**

*"Good quality services (this might mean that LCC will need to select the services that are more expensive rather than commissioning those that are the least expensive)."*

*"Support at the right time at the right quality and in the right quantities when we need it!"*

### **Phase 5**

- **Managing at more difficult times, including if possible to live at home**

## **Hospital care**

*"Care - Enough staff to provide proper care to ensure patients eat and drink, are not left in soiled beds and are not discharged with bedsores. Ensure they are clean and smell nice. Allow a hairdresser to visit the ward. Employ staff who are able to treat patients with dignity, respect and understanding. Employ staff who can read patients notes so they are aware if there is a diagnosis of dementia. Allowing carers more visiting time and to let them help care. Listen to carers who know the patient the best. Do not put a "Do not resuscitate" sticker on their file without consulting with family. Sack people who are of no use such as those who write fantasy novels - sorry, strategies and replace with staff who can provide practical help i.e. staff who have a bit of common sense"*

15

# Adult Care

*"That the staff understand the individual's needs. That they have empathy and sympathy. There was none of this when Dad was in hospital. It was shocking."*

*"Talking with the dementia patient and explained what is going on - even though they may not know what it is that is being said they are aware that something is not right - giving them the option to understand is important."*

*"Correct procedures being followed on discharge to manage a person's risks when returning home. If the family request an assessment, where the patient lacks capacity in this area, this should be actioned."*

## Phase 6

### • Receiving care, compassion, and support at the end of life

#### A good death

*"That the person I care for has a 'good' death - i.e. in a comfortable non-clinical environment."*

*"Knowing my grandma was a proud woman and died in her own home and was clean and looked after by us."*

*"Knowing that the patient has died with dignity, being cared for but without unnecessary medical intervention."*

*"Make sure that everything is done that should be done - according to what we have planned."*

#### Key themes that cut across the journey

There were other key themes that emerged as a result on the consultation, that were important to our respondents throughout the entire journey, not just within one phase. Those issues are highlighted below and illustrated by the comments of some of our respondents: -

#### Recognising the family of people with dementia and the people (usually family) who care and allowing them to have a voice

*"Listening to Carers who know the patients' needs best."*

16



# Adult Care

*"Hospitals need to inform relatives /carers of their proposed date for release of patient, I was on standby for a week and then told off because I couldn't pick him up immediately when they chose to release him on a Monday which is my busiest day of the week."*

*"Recognition and acknowledgement from health professionals regarding the impact the condition has on person and their family."*

*"LCC, NHS expect to, and have salaries, training and working conditions. Carers should be given the same - think about the carer. Who looks after the carer(s)?"*

*"Support for carers and involvement in care/decisions."*

*"Appreciation that carer(s) have special knowledge of how to care for the patient, and the severity or not of the individual's particular condition. Patients with dementia covers a huge spectrum."*

## **Helping people with dementia and their families and carers with financial information and assistance with benefits**

*"More advice/signposting to financial/benefits advice."*

*"Proactive assistance with claiming benefits including DLA, Council Tax exemption (we were 12 months before friend told us that my Mother could claim these). Thankfully Age Concern knew exactly and helped to complete the complicated lengthy form. None of the professionals advised my Mother about these financial benefits."*

*"Recognition of the financial burden of caring for a family member (loss of income and reliance on benefits."*

### **Key themes relating to systemic and staffing issues**

Other key themes emerged that were related to how our respondents felt about the ability of staff within the health and social care arenas to care for people with dementia and the trials and tribulations of dealing with the system itself. Responses illustrated by the quotations listed below: -

### **Training for health and social care staff about dementia**

*"Better training for those people working with people with dementia e.g. homecare providers, care homes."*

17

# Adult Care

*"Compulsory training for professionals who work with people- e.g. ALL hospital and nursing staff, not just people who have direct contact with people who have Dementia."*

*"All Health and social care professionals having awareness of and being taught about dementia and its symptoms and how to cope, in all settings of hospital and community care settings."*

*"Understanding of the condition by nurses and doctors. When mum was last in hospital the doctor was asking her questions she didn't understand and taking her yes/no response as genuine."*

*"Understanding of the dementia and how it affects the individual and the anxiety caused by admission to hospital and change of routine and unfamiliar surroundings."*

**Having a clear pathway through the system to make it user friendly – A seamless service across health and social care.**

*"Knowing what help was available to enable us to live as 'normally' as possible at home, but with support."*

*"Information. Mum was discharged from hospital after a stay of 6 weeks and I was told she had dementia. I was given no information about what to do, where to go for help, or what to expect from the illness."*

*"A list of anyone who could have become involved with the family and helped us to understand. One to one care (e.g. volunteer coming in to tell us everything we needed to know) instead of endless separate services. All too confusing and not much help at all. Worked it all out ourselves  
GP should refer you to a specialist dementia team who should then contact the individual/carer to assess on-going needs and to be a point of contact for the sufferer/family."*

*"One person to contact who co-ordinates and is proactive to making things happen. Phoning all the different organisations and professionals is time consuming and expensive - remember many dementia suffers and their carers are receiving pensions and not receiving a salary. The carer's time becomes consumed by looking after the patient."*

*"Knowledge about what is available and suitable for the person concerned. There are far too many leaflets etc which do not specify how they would help specifically and are far too difficult to access when time is precious being spent on caring for the person with dementia. Carers do not have the energy or time to go through reams of paper looking for something which MIGHT help. Too much money is being wasted when resources should be being pooled and organised to give the right help to the right person."*

18

# Adult Care

*"More 'joined up' thinking and working together of the various bodies who are part of the dementia journey and can help families think ahead and prepare for, e.g., end of life.*

*"Meaningful joined up working from health and social care- not just a case of whose responsibility is it?"*

## Findings

### Awareness of Lincolnshire Joint Strategy for Dementia 2010 – 2014

The results concerning the awareness of Lincolnshire Joint Strategy for Dementia 2010 – 2014 were broadly that most of the respondents were aware of its existence. There is broad agreement that amongst health, social care and voluntary sectors, there has been an improvement in dementia related services. However, this view is not consistent with banks, shops, supermarkets and the general public. Notably, our respondents do not think that the Lincolnshire Joint Strategy for Dementia 2010 – 2014 has had a positive effect upon attitudes of employers which has a significant impact upon carers in employment.

Our Respondents told us the following from their contributions towards the Lincolnshire Joint Strategy for Dementia 2010 – 2014 Refresh: -

- There is a great deal of importance put upon having an early diagnosis in order to give information about what to expect and a measure of control to people with dementia and their families and carers
- There is a need for clear information about dementia and about services that are available
- There should be information and training available for families to increase their own knowledge about dementia
- There needs to be more awareness concerning dementia in the public domain
- People want to be treated with dignity and respect and have their voices heard when it comes to their own and their loved ones care and treatment
- There should be adequate funding for care and support to ensure decent standards
- Staff working within health and social care who care for or treat people with dementia should be properly trained

19

# Adult Care

## Phase 1

- **When memory or changing behaviour problems have prompted me, my family or carer to seek help**

The overwhelming majority of people went to their GP as a first port of call for information and help when the first signs of dementia started to appear. Other notable sources of information and help were family and friends, voluntary organisations and the internet. Many of our respondents knew where to go when memory problems first started to appear.

Our Respondents told us the following from their contributions towards the Lincolnshire Joint Strategy for Dementia 2010 – 2014 Refresh: -

- There is a need for community based care and support services to enable people with dementia to remain at home for as long as possible
- The pathway to access care and support at home should be as user friendly and straightforward as possible
- There should be greater integration across health and social care

## Phase 2

- **Learning that the condition is Dementia**

20

Experiences of our respondents at this stage of the dementia journey can be described as mixed. For example our respondents in the carers, Lincolnshire residents and health and social care professional groups were positive when asked if after diagnosis health and social care staff were understanding, made clear the need for diagnosis and gave clear information about other services and what options were available. There was some degree of exasperation at the difficulty in navigating the health and social care systems by some of the online questionnaire respondents

Our Respondents told us the following from their contributions towards the Lincolnshire Joint Strategy for Dementia 2010 – 2014 Refresh: -

- They would like to have someone to talk to
- Staff within health and social care should have a better understanding about dementia and its effects
- Clearer knowledge about where to go for help
- Having a single point of contact to help with navigating health and social care services
- Staff in health and social care were understanding and tried to help with information and treatment options

# Adult Care

## Phase 3

- Learning more about the disease, how to manage, options for treatment & care, and support for me & my family & carers

When asked whether a care plan had been completed for the person with dementia, most of our respondents had not. Of those that had, just over half stated that the needs of the person with caring responsibilities had not been taken into account. Under the terms of the new Care Bill, this requirement will be enshrined in law. Carers in many cases had been offered carers assessments and emergency response plans. Our carers and health professionals groups thought that people with dementia who asked for help would receive it and that families were told about the help and support that is available

Our Respondents told us the following from their contributions towards the Lincolnshire Joint Strategy for Dementia 2010 – 2014 Refresh: -

- There is a need for easily accessible and affordable respite care
- Community based services are essential to help reduce isolation
- Peer groups of people going through the same circumstances are important
- People living with dementia and their families and carers want financial support and help with benefits

21

## Phase 4

- Getting the right help at the right time to live with Dementia, prevent crisis and manage together

When asked what helped people with dementia and their families to live as we as possible with dementia, the most important options listed were the support of family and friends, support for the carer, knowledgeable and easily accessible professional help and support, and home care support. Most of our respondents felt that people with dementia and their families can get help to stay at home, but there were mixed views as to the quality of that support. Most of our respondents felt that they were coping as a family or a carer, but that it was a struggle and they sometimes felt like they were "on their own"

Our Respondents told us the following from their contributions towards the Lincolnshire Joint Strategy for Dementia 2010 – 2014 Refresh: -

- There is a need for easily accessible day care
- A sitting service should be available to give carers a break
- Carers should be valued much more than they feel they are at present

# Adult Care

## Phase 5

- **Managing at more difficult times, including if possible to live at home**

When things get harder, people with dementia, their families and carers go to a wide range of different places in order to get help, support and advice ranging from their GP, their own family, The Lincolnshire County Council Carers Team and voluntary organisations such as Dementia South Lincs and the Alzheimers Society. Our respondents told us that they would value a single point of contact they know and trust. Many of the responses in this section were concerned with what happens when someone with dementia is admitted into hospital. There is a wide consensus that experiences of people with dementia and their families and carers are inconsistent and mixed when accessing hospital or residential care.

Our Respondents told us the following from their contributions towards the Lincolnshire Joint Strategy for Dementia 2010 – 2014 Refresh: -

- Better, high quality care by an adequately staffed hospital
- The person with dementia to be discharged as soon as possible with the right support
- People with dementia, their families and carers to be listened to by staff in hospitals, they do, after all, know the person with dementia better than anyone else
- Ensuring that people with dementia have been identified correctly to ensure that the appropriate care is given
- That the hospital environment is suited to the needs of people with dementia

22

# Adult Care

## Phase 6

### • Receiving care, compassion, and support at the end of life

In the last part of our consultation, views were sought as to what matters to people with dementia, their families and carers at the end of life. This is a very emotive subject and the responses we received reflected this. Most of our respondents when asked if they thought that when people with dementia near the end of their lives they are treated with compassion and their views were respected, agreed with this statement. We also asked what was important to them.

Our Respondents told us the following from their contributions towards the Lincolnshire Joint Strategy for Dementia 2010 – 2014 Refresh: -

- The exercise of choice with regard to the manner and location of death is a priority
- Early planning is essential in order to ensure that choice can be exercised at the end of life
- The person with dementia's wishes are honoured
- The family and carer are supported through the grieving process

## Early Onset Group Analysis

### Early onset dementia

A group of 22 members of The Square Hole Group discussed aspects of the dementia questionnaire at one of their regular meetings. Membership was of approximately equal numbers of people with dementia under age 65, and their carers or family members.

There was a general view that the needs of people of working age affected by dementia were likely to differ significantly from those of older people. There was a consistent view that younger people needed more individualised support to include, among other elements, recognition of employment and relationship factors.

Members of the group highlighted the need for people to have access to appropriate day time activity rather than traditional models of day care accessed by older people. There was a view that voluntary groups and organisations play a valuable role in providing support services but that services still need to be professionally led and co-ordinated . Voluntary support groups are seen as a cost effective way of supporting people affected by dementia and there was a wide spread view that the voluntary sector should be better supported by statutory bodies.

General themes emerging from discussion included the need for integration of health and social care services. The need for consistent, accurate information and a single access point were also stressed.

Nationally, there are calculated to be more than 13,000 younger people with dementia. In Lincolnshire the numbers are estimated at about about 200 (Source : PANSI, 2012).

There are sometimes significant age-related barriers for younger people trying to get access to dementia services. If no specialist services exist, younger people with dementia can find themselves lost between services, none of which will accept responsibility for their care.

Even if dementia services accept younger users, the type of care they provide may not be appropriate.

Some people with dementia may want to continue working for some time after their diagnosis, or may wish to take early retirement if this is appropriate. Carers may also want to continue working, or may be concerned about giving up work to care full time. If the person has children it is important that they understand - in an age-appropriate way - what dementia is, how it affects their parent and what changes to expect. Every child is different and will react in their own way.



## **Dementia Consultation: - Acknowledgements**

The authors of this report acknowledge the views and contributions made by everyone who completed a consultation questionnaire either on-line or in hard copy. In addition, our thanks go to statutory and voluntary agencies, individuals and groups who have submitted comments directly or through discussions at a range of meetings and workshops. Groups and agencies concerned include, but are not restricted to: -

Age UK

Alzheimer's Society

Boultham Park House Memory Café

Dementia Support South Lincs

East Lincolnshire District Council

Healthwatch

Lincolnshire Carers' and Young Carers' Partnership

Lincolnshire Community Health Services NHS Trust

Lincolnshire County Council Adult Care

Lincolnshire County Council Public Health

Lincolnshire Partnership NHS Foundation Trust

South West Lincolnshire Clinical Commissioning Group

Square Hole group

St Barnabas Hospice

# Adult Care

## Appendices

### a) Sample Responses and Data from the Lincolnshire Joint Strategy for Dementia 2010 – 2014 Refresh Online Consultation Questionnaire

#### Awareness of Lincolnshire Joint Strategy for Dementia 2010 – 2014

The first part of the consultation was concerned with how much awareness there was amongst the respondents of the current Lincolnshire Joint Strategy for Dementia 2010 – 2013.

The first question of the consultation was - Are you aware of the current Joint Lincolnshire Dementia Strategy?

Yes	47
No	37

The survey went on to ask – Has the Joint Lincolnshire Dementia Strategy helped improve outcomes for people living with dementia?

Yes	7
No	14
Don't know	26

It is worth noting that only around half of the respondents to the questionnaire answered this second question. The survey went on to ask: -

Do you think attitudes and awareness towards people living with dementia has improved in the last three years since the launch of the National Dementia Strategy and Lincolnshire's Joint Dementia Strategy?

	Yes	No	Don't know
Healthcare professionals (e.g. GP, nurse)	38	24	20
Social workers	31	22	28
Care providers	36	24	19
Voluntary organisations	45	13	22
Shops, banks, supermarkets	10	45	23
Employers	8	39	31
Friends	34	30	15

26

# Adult Care

General public

19

42

19

## **Narrative responses under any further comments were categorised and below is a cross section of entries**

*"Attitudes to dementia sufferers are still poor, doctors and nurses still have poor insight into caring for someone with dementia and the dementia is always seen as a barrier to the care the patient receives. Care workers are still not trained enough in dementia care especially how to deal with someone who has dementia and behaviours that challenge. Care providers are not financed enough to allow the level of staffing to make a real difference to the standard of care and life the dementia sufferer receives. The general public are becoming more aware of dementia and what this means because it is spoken about more but there are still so many misconceptions."*

*"I also believe the County Council struggles to realise the effect dementia has on a person's ability to live independently, and tries to duck the issue by taking away the help provided and replacing it with a self-managed fund."*

There were 14 narrative responses in this section. The survey went on to ask respondents – What is important to help improve attitudes and awareness towards people living with dementia? Please list up to five priorities

27

The comments were categorised as follows: - with the category with the most responses coming first and so on. (The number of responses under each category is shown in brackets)

### **Early diagnosis of dementia and early intervention (17)**

*"Early diagnosis of dementia - and being open about the condition which is still stigmatised."*

*"Early diagnosis, because so many are just labelled 'confused' right now."*

*"Simply testing a sufferer once a year or every six months will not show the extent of progress of the problem and this is what happens when somebody is referred to the mental health service initially. This delays diagnosis."*

### **Clear Information, publicity, support and awareness (97)**

*"More publicity about the condition - maybe famous people who have been through it with relatives speaking out. More literature available in public places e.g. GP surgeries and libraries."*

*"Increase understanding of dementia and how it affects those with the disease."*

*"To make more people generally aware of dementia and its impacts many people have many misconceptions about dementia, and its stages. Greater awareness is imperative if dementia sufferers are to continue to live a life as normal as possible for as long as possible."*

*"More publicity! Many people are still under the illusion that people with dementia have 'memory problems'. It becomes apparent very quickly that it is much more than this, that dementia results in a myriad of practical issues (housing, money, care to name a few) that are incredibly difficult to deal with."*

*"How the condition affects those who care for the sufferer and impacts on their family. Carers need recognition and maximum support."*

## **Recognition of the condition, reducing stigma, recognising the carer and treating people with dementia with respect (65)**

*"There needs to be greater tolerance by the general public of the condition and compassion shown when sufferers are out in the community."*

*"To listen very carefully what the person is saying."*

*"Recognition that dementia is an illness in its own right - it cannot be 'lumped together' with 'mental health'."*

## **Increased help in the community and adequate funding for services (22)**

*"Adequate clubs and social events for people with dementia and family/carers."*

*"Adequate funding to support dementia patients and carers."*

*"Funding for integrated services: if the GP knows you have dementia, you shouldn't have to explain that again at the hospital or dentist."*

## **Better Training for Health and Social Care Staff (38)**

*"Adult Social Care and NHS training in dementia awareness."*

*"Dementia Champions - across the county to support people with dementia and their carers in social situations - support groups are integrated into the community - different organisations take on roles for their local groups - offer service or discount to those living with dementia."*

*"Making sure GPs understand the symptoms and prioritise their patients rather than their schedules and surgery budgets."*

# Adult Care

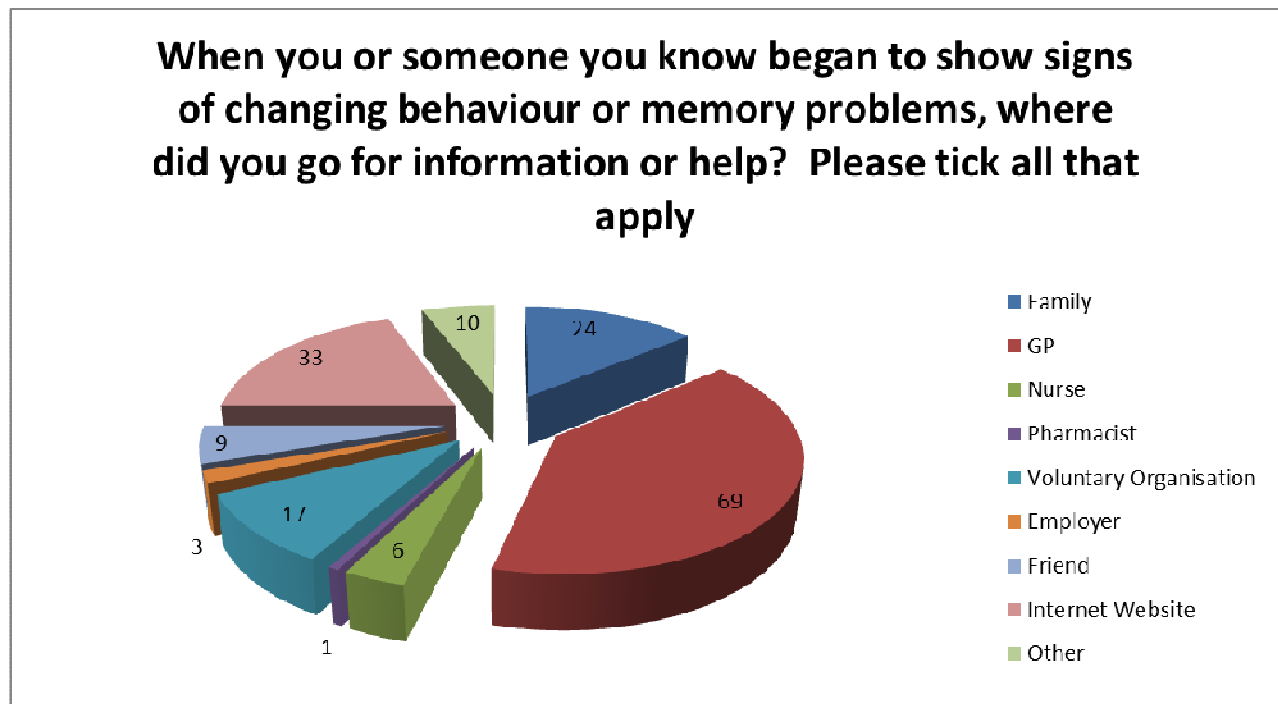
## Phase 1

- When memory or changing behaviour problems have prompted me, my family or carer to seek help

Phase 1 of the dementia journey deals with the initial period when the person with dementia first starts to show signs of changing behaviour or memory problems.

The consultation asked respondents about their experiences at this stage including where they went for information and help and what they found most or least helpful at this stage.

The respondents were also asked to what they thought would have helped at this stage and to prioritise their suggestions.



29

Of those seeking information and help from voluntary organisations, the majority contacted the Alzheimers Society (9 of 17). Other organisations mentioned include Age UK and Dementia Support South Lincs. The most common sources of information on the internet were also the Alzheimers society and Google searches under dementia.

# Adult Care

**Narrative responses as to what support would have helped when the first signs of dementia started to show.**

The respondents to the survey were asked to state what they thought would have helped at this stage and to prioritise their suggestions.

The comments were categorised as follows: - with the category with the most responses coming first and so on. (The number of responses under each category is shown in brackets)

**Clear Information and knowledge about what help and services are available. A single clear point of information required (38)**

*"One central informed source of info - a Gatekeeper."*

*"Advice about the most suitable help available for the person concerned. There are too many leaflets and people doing the same job or similar."*

*"A named person to contact for advice, even within a voluntary service, just to talk and share fears."*

30

**Better services to be available in the community including access to respite care, and access to financial and benefits advice and assistance (47)**

*"Somewhere or someone to help keep our father stimulated rather than him sitting in the chair giving in to the dementia."*

*"Services which enables the person to continue with community independent living."*

*"Better access to respite support - quicker and more user-friendly"*

*"Someone to sit with my Mother, the carer, on her own and explain the diagnosis, how to care for patient, how to care for herself, and to describe what would happen as time went on. To provide her with contact details rather than expect her to write them down. Professional(s) have years of training and experience in the work place, I find it difficult to understand how there was an expectation that my Mother would just get on with it without training including moving and handling training, understanding how to respond to my Father's memory loss, aggression, confusion etc."*

**Earlier diagnosis, intervention and help from GP's, including greater information about dementia (24)**

*"Being given information about the condition, and likely progression at the time of diagnosis. I had to find this out for myself."*

# Adult Care

*"More information on early onset Dementia- information given in language that is easy to understand, not medical terminology."*

*"Time with primary care team, GP/Nurse Practitioner, to discuss symptoms, diagnosis, prognosis and treatment/care plan."*

**Need for dignity and respect of both the person with dementia and their carer and family. (Includes issues such as being given access to information for family and carers to NHS/Social Care and confidentiality issues with banks etc) (18)**

*"Listening to Carers who know the patients' needs best."*

*"Active involvement and engagement of dementia sufferers and their families in commissioning and development of services."*

*"Lincolnshire County Council - NHS expect and have salaries, training and working conditions. Carers should be given the same - think about the carer. Who looks after the carer?"*

**The need for joined up co-ordinated services across health and social care. A clear pathway. (13)**

*"More joined up information about how to care for our loved one at home. We had to work it out ourselves with help from friends and family. GPs should be armed with all information for all areas of Lincolnshire. We would have then had support that was relevant to our needs."*

*"Proactive referral to other services (joined up services) - including looking ahead not just at the diagnosed stage."*

*"A totally coordinated approach using health, social care and other services. Not "well dear you may need to contact your GP as it is a health matter and we are social services". A hub approach where all services are together and whoever receives the call deals with the issue."*

31

# Adult Care

## Phase 2

### • Learning that the condition is Dementia

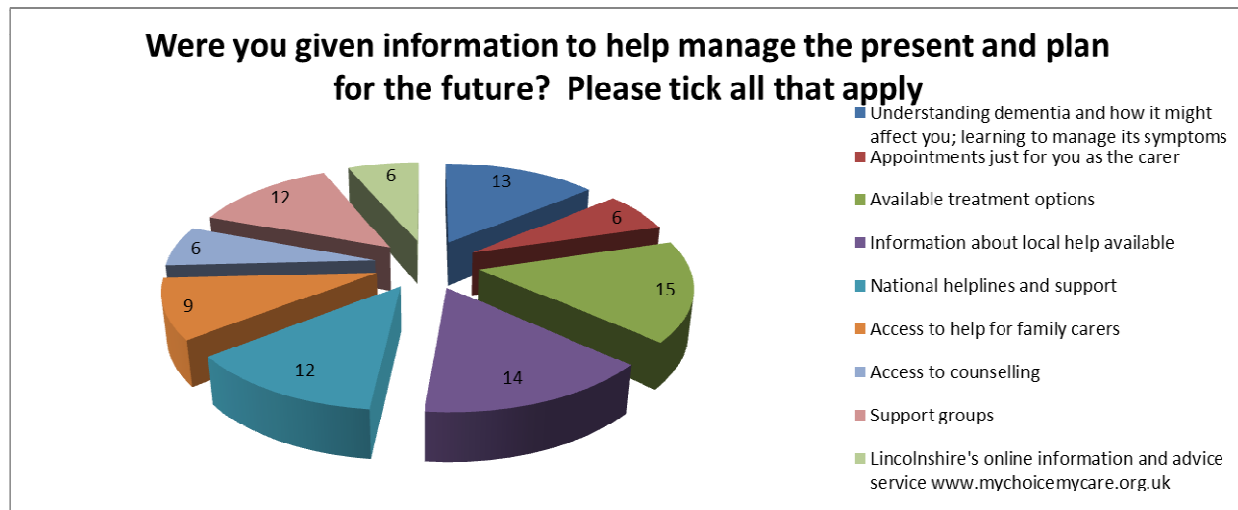
Phase 2 of the dementia journey is concerned with what happens at the time that a diagnosis of dementia is made. This may involve many conflicting emotions such as: - fear, anger, sadness, bitterness, despair, isolation and helplessness for people receiving a diagnosis of dementia, as well as their friends, families and carers.

The consultation asked respondents if they or a loved one had received a diagnosis.

44 people ticked yes, 38 no and 4 did not know.

The consultation then went on to ask if they were given information to help manage the present and plan for the future.

The responses can be shown in the pie chart below;



32

The respondents were then asked to tell us about their experiences

#### Negative Concerning NHS Treatment (7)

*"Information was initially scarce and much of the information was via self-research. The criteria for receiving help were not readily available (and were only found out through a family friend who dealt with welfare benefits as part of their own job). The medical profession when dealing with a hospital*



# Adult Care

*admission from a fall did not give full information - and did not listen to the individual's needs, this proved a difficult time and turning point in the journey which led to confusion and added stress on the family. It created mistrust and in my opinion delayed the support required at that time."*

*"Generally a poor experience of assessment, diagnosis, prognosis and treatment options."*

## **Positive Concerning NHS Treatment (2)**

*"Support was given from CMHT which was more tailored to the needs of the individual but which took time to build and gain that trust. This is an area which worked well as they understood the dementia journey and were able to take the time to explain in a way that was understood and recognised."*

## **Negative Concerning Adult Social Care Services (4)**

*"The Lincolnshire Social Services and County Council along with the health support team were abysmal. They completely ignored the aspect of Dementia"*

*"My 83 year old father-in-law has recently been diagnosed with Dementia and is cared for by his 81 year old wife. They do not have access to on-line info and whilst I can help with this I am quite frankly overwhelmed with the shear volume of info. My in-laws are of an era where they want the personal touch and advice not just information but after contacting social services by phone they have had one visit in the last 12 months which was just to see if they needed any help with devices around the house. Quite frankly we feel that we have just been left to try and figure it out as we go along and get on with it and sort out any services we may need ourselves but this is quite difficult when the person suffering the illness refuses to acknowledge there is anything wrong"*

33

## **Positive Concerning Voluntary Organisations (2)**

*"The Alzheimers Society initially helped and supported but the name of the society is off-putting initially when you are grieving about the diagnosis. They helped with the legal side and to have a plan in place in an emergency"*

## **Narrative responses to what respondents thought would have helped most after diagnosis.**

The survey then went on to ask respondents what they thought would have helped most after diagnosis, and to list five priorities

The comments were categorised as follows: - with the category with the most responses coming first and so on. (The number of responses under each category is shown in brackets)

# Adult Care

## **More practical help and support for service users and their carers including respite care, financial and benefits information. (44)**

*"Help in the home, of a practical nature. I am a lone person looking after my partner and sometimes just another pair of hands would mean all the difference."*

*"Practical daily help. Affordable help for the person to do daily living and household tasks. These increased for me as a carer and I couldn't hold down my job, look after my children and help my mum with her physical disabilities."*

*"Information and support in dealing with what's next - available options to build a tailored support plan."*

*"Financial information and where to obtain support."*

## **Clearer information and knowledge about what help is available – A single point of contact (36)**

*"Knowing what help was available to enable us to live as 'normally' as possible at home, but with support."*

*"Information. Mum was discharged from hospital after a stay of 6 weeks and I was told she had dementia. I was given no information about what to do, where to go for help, or what to expect from the illness."*

*"A list of anyone who could have become involved with the family and helped us to understand. One to one care (e.g. volunteer coming in to tell us everything we needed to know) instead of endless separate services. All too confusing and not much help at all. Worked it all out ourselves"*

*"One person to contact who co-ordinates and is proactive to making things happen. Phoning all the different organisations and professionals is time consuming and expensive - remember many dementia suffers and their carers are receiving pensions and not receiving a salary. The carer's time becomes consumed by looking after the patient."*

## **More information about dementia including training for the public and for staff working within health and social care. (26)**

*"Better training for professionals including district nurses who visit the home"*

34

# Adult Care

*"Information - I was never made aware of the stages of dementia or what to expect. I was not prepared for how emotionally and physically draining being a carer would be or how difficult it would be to even contact professionals let alone get advice or assistance from them."*

*"That Lincolnshire Social Services and the County council, care workers are sent on a comprehensive training course to learn about dementia. It is not rocket science, but they appear to be unable to recognise Dementia. Lincolnshire Adult services are totally unable to recognise any issues regarding dementia."*

*"Having more information about the condition."*

**Dignity, care, compassion, respect, understanding, empathy including issues around Power of Attorney for carers. (12)**

*"Support from District Nurses, Social Workers and Occupational Therapists all of which were totally lacking in compassion and understanding whilst I struggled to care for and keep safe the most precious person in my life."*

*"Compassion, kindness, understanding and respect."*

35

# Adult Care

## Phase 3

- Learning more about the disease, how to manage, options for treatment & care, and support for me & my family & carers

Phase 3 of the dementia journey is concerned with the stage after the initial diagnosis and information gathering. It is about taking the next practical steps and organising options for treatment, organising care and getting support for the person with dementia, their family and their carers.

The consultation asked respondents whether they had had an assessment of their care needs, and been given a care plan. 70 of the respondents answered this question, 29 answering yes and 41 and answering no.

The respondents were the asked to state if a designated list of organisations or care professionals were involved in the assessment process. The responses were as followed: -

GP	4
Lincolnshire Foundation Partnership Trust	1
Psychologist	3
Occupational Therapist (OT)	6
Neurology	0
Old age physician	0
Lincolnshire County Council Adult Services	15
Carers Team	10
Voluntary organisation	9

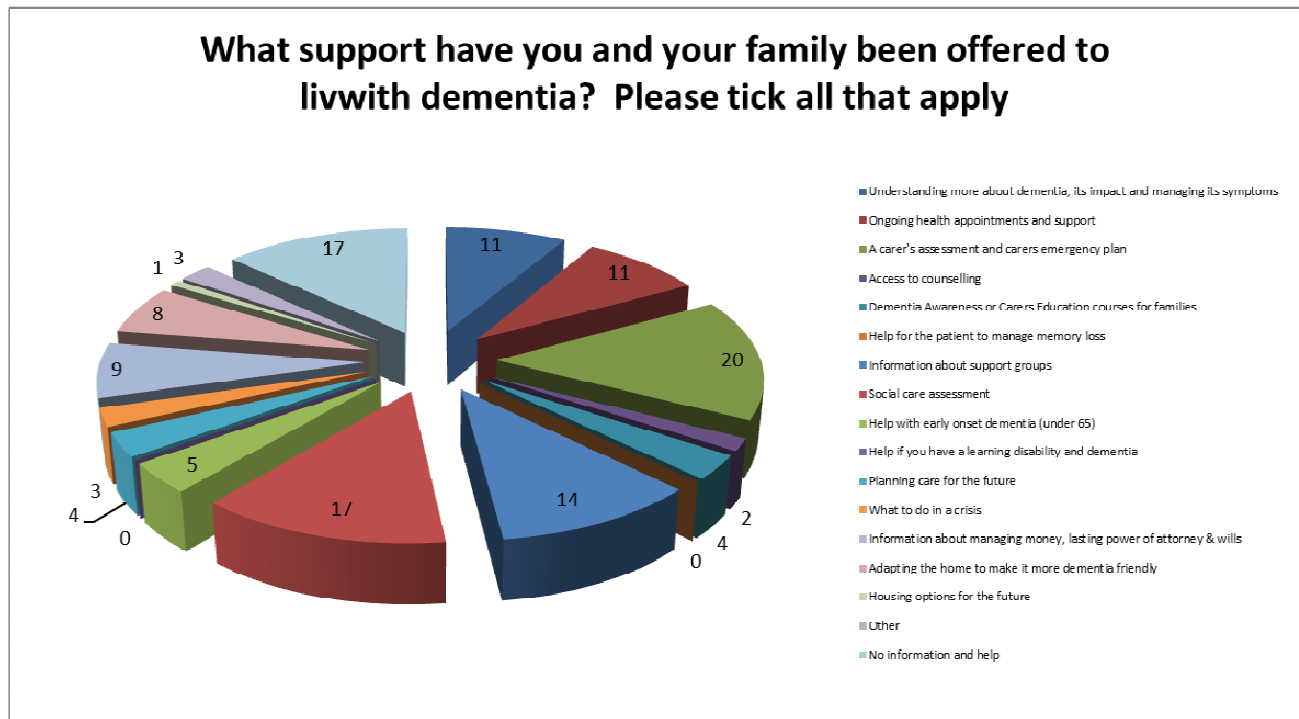
36

Respondents were then asked to state whether they found the aforementioned organisations or professionals helpful.

Respondents were also asked if they felt that their needs as a carer were taken into account during the assessment of care needs. 33 of the 77 respondents stated that this was not applicable. Of the remaining 44, 19 (43.2%) stated that their needs as a carer had been taken into account, 25 (56.8%) stated that they had not.

The survey then asked what support service users and their families had been offered to live with dementia, the results were as follows: (NB respondents were able to make more than one response)

# Adult Care



37

Opinions as to the helpfulness of the above support were again sought which were broadly rated as helpful (57.4% of respondents opting to classify the support in the top 2 categories of helpfulness as opposed to the 15.7% who classified the support in the bottom 2 categories).

**Narrative responses respondents made when asked to give their top five priorities to help families learn about managing living with dementia and to plan for the future.**

Respondents were asked to list their top five priorities to help families learn more about managing with dementia and to plan for the future.

The comments were categorised as follows: - with the category with the most responses coming first and so on. (The numbers of responses under each category are shown in brackets)

**Support and services including respite care, adaptations and dementia friendly environments. (37)**

*"Respite Care needs to be explained and more must be made available at short notice to help families in crisis."*

# Adult Care

*"Being able to get my partner to go into respite, he calls the shots if he does not want to go then I have to accept it. One day I shall drop with exhaustion then what!"*

*"Information on home adaptation e.g. contrasting colours, labels on drawers / cupboards"*

*"Specialist dementia social care/support at home."*

## **Awareness and training concerning the condition (34)**

*"Training - i.e. opportunities to take a 'course' or awareness session led by people who know what it is like to live with dementia."*

*"Literature on the condition rather than being told the names of organisations. My Mother doesn't have access to a computer and would (not) know how to use one. Think of the carer and the news - overwhelmed with looking after the patient, and the loss (of the partner and lifestyle) - every task that professionals suggest seems too much. Someone with knowledge to sit down and talk to the carer to explain what (it) is and (what) will happen."*

*"Understanding the dementia journey: what stage are we at now and what help we can have, and what is likely to happen next and what support will be available then."*

38

## **Navigating the system/information/co-ordination/face to face advice/pathway – single point of contact (30)**

*"Ensure a care plan is completed at diagnosis and takes into account the future so when the carer experiences/recognises a new stage there is one contact point and services proactively respond. Avoid crisis. Look after the carer - this is the person who becomes the professional - the nurse, carer, form filler/administrator, occupational therapist etc."*

*"Information and knowledge about steps to take as in palliative care to prepare for future."*

*"What support is available for staying at home in the short, medium and longer term?"*

*"Send in a highly trained volunteer to help with it all. You don't want a whole load of people coming at you from all angles it's too confusing. One caring person who knows it all and can become a friend and support throughout."*

# Adult Care

## **Listening to the patient and their carer, dignity and respect (15)**

*"Support for and understanding of the feelings of anger, loss and guilt that the carer goes through. Access to someone to talk to who understands."*

*"Listening to families as well as patients – they (patients) sometimes disguise the truth."*

*"Making sure people (person with diagnosis and their family) are kept informed and involved throughout the whole process."*

## **Joined up co-ordinated services across health and social care (8)**

*"Meaningful joined up working from health and social care- not just a case of whose responsibility is it."*

*"Do not split health and social care funding"*

*"Joined up services that refer and communicate with one another on behalf of the carer/patient."*

## **Financial support including benefits and housing and power of attorney issues (6)**

*"It can be helpful to plan money matters especially to persuade the person with dementia (earlier on) to think about power of attorney over finances."*

*"Need information about finances and power of attorney."*

*"I currently need housing options because we have been served with notice due to my partner's behaviour."*

39

# Adult Care

## Phase 4

- Getting the right help at the right time to live with Dementia, prevent crisis and manage together

Phase 4 of the dementia journey is concerned with managing to live well with dementia. At this stage the focus is on getting the right help at the right time in order to prevent crisis and maintain a good quality of life.

The survey asked what helped people with dementia and their families to live as well as possible with the condition. A range of options were given such as telecare, day services, accessible transport etc. The 4 most selected options were could all be themes as "support": -. These were also rated as most helpful.

- 1) Support of family and friends
- 2) Support for you as a carer
- 3) Easy to contact knowledgeable help and support
- 4) Home care or other paid support in the home

Some examples of personalised daytime support were sought from the respondents: -

40

"Dementia affects different people in different ways - support needs to be tailored for the person. E.g. to continue to carry out activities that have been enjoyed/fulfilling. The traditional 'day centre' of people sitting in a room playing bingo is not appropriate for someone who has never previously wanted to play bingo!"

"Opportunities to participate in community & daily activities that provide stimulation, enjoyment and help to enrich life - provided with dignity and respect."

Respondents were asked to state how they felt they were managing day to day living with dementia.

	Yes	Sometimes	No
Feel you are managing on a daily basis	13	23	7
Have the right level of support	5	20	20
Know where to go for more help	15	13	16
Feel isolated	15	27	3
Struggle to cope	14	28	2



# Adult Care

The results of this question were mixed. The framing of the question led to mixed responses for example, when asked if they felt they were managing on a daily basis, 13 said yes and 7 said no. When the same respondents were asked if they were struggling to cope, 14 said yes and 2 said no.

Many respondents went on to make further comments which are telling as to how they feel about managing to live well with dementia: -

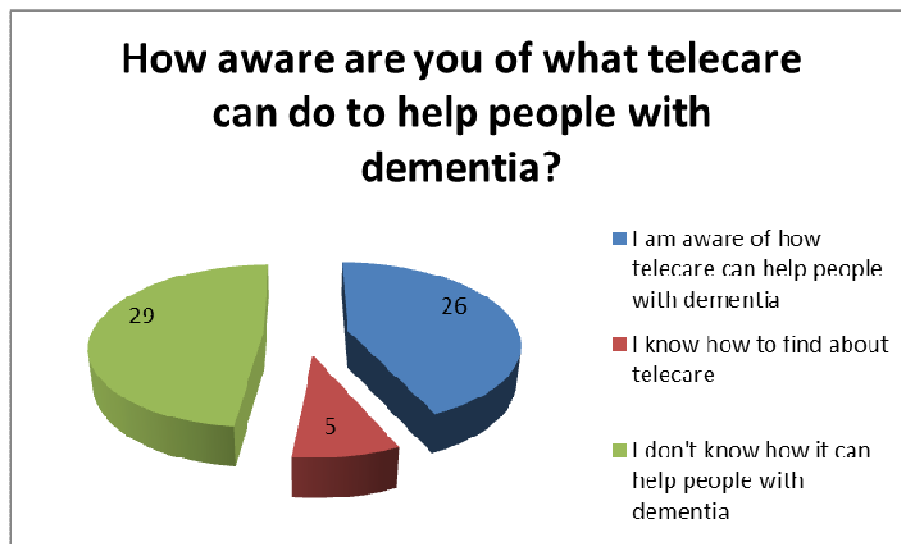
*"Everything is made difficult for example District Nurses were asked if the carer could be given their flu jab when the bed bound patient received theirs during a home visit. Of course not! Someone had to look after the patient so the carer could make an appointment to receive theirs at the surgery."*

*"I am a lone carer and I work full time in a pressured job. It is very hard and I feel like I am coping on my own apart from the day centre. The Consultant advises that Social Services are the people to assist, but we don't have a named S(ocial) W(orker) so you have to speak to somebody new every time you ask for help."*

*"We had to pay for a private carer in the end for the day times due to the short amount of time the council carers were allocated to each person and the lack of day centres in the area. With work, we as a family could only have the evening and weekends to look after her which could be wearing for 4 years our lives were work and looking after my gran"*

41

The survey went on to ask how aware the respondents were of what telecare can do to help people with dementia. The responses are illustrated below: -



# Adult Care

## **Narrative responses respondents made when asked list the improvements they thought would be most helpful to people with dementia and their families in their own part of Lincolnshire**

The comments were categorised as follows: - with the category with the most responses coming first and so on. (The numbers of responses under each category are shown in brackets)

### **Knowledge of and access to services and support in the community and at home (55)**

*"Knowing about support groups - being able to talk with people making a similar journey."*

*"More local support groups for both carers and people living with dementia in villages. Not everybody can travel."*

*"An individual and personal care plan for the carer and the person with dementia with regular reviews (such as those for special needs children in schools)."*

*"Support at the right time at the right quality and in the right quantities when we need it!"*

*"Good quality services (this might mean that LCC will need to select the services that are more expensive rather than commissioning those that are the least expensive)."*

*"Consistent Carers, so they can get to know each other. A person with a need, rather than just a need that has to be filled in the time slot allocated."*

42

### **Breaks for carers including access to respite, day care and carers support services (17)**

*"Realistic support. £250 a year, whilst better than nothing, does not cover the costs of a holiday."*

*"Respite care to give carers a break or so they can do simple tasks such as the shopping."*

*"Sitting Service or buddy service in the early stages where for example someone who likes gardening could have come to the house and helped Dad in the garden as he forgot how to do things, when to set things etc or how to carry on making his wine. It would have helped him to continue to feel useful."*

*"Day centre activities for those with dementia to give carers a break and enable sufferers to enjoy other company."*

*"Access to pre-planned, guaranteed, bookable Respite Care. This is THE issue for me."*

## **Knowledge of dementia for public and for those working within health and social care (13)**

*"Public awareness to help with embarrassment when out in the community"*

*"It would be a great help if professionals understood dementia better than the carer so questions could be answered and practical help and advice given."*

*"Better training for Care Providers. Again, they seem to think that everyone with Dementia doesn't understand normal conversation and so talk to them in a childlike fashion."*

## **Issues around dignity and respect such as listening to the family and carers. Being honest and having compassion (8)**

*"Not having to plead for help"*

*Kindness, compassion and honesty"*

## **Co-ordinated care and support across health and social care (5)**

*"Being able to streamline everything across agencies - i.e. them sharing information and co-ordinating assessments, home visits, appointments, etc."*

*"Joined up thinking by professionals who have the ability to provide real help and support. This to include GP, district nurse etc. Greater and more effective training for professionals."*

## **Financial help and advice including benefits advice (4)**

*Recognition of the financial burden of caring for a family member (loss of income and reliance on benefits)."*

## **Narrative responses respondents made when asked list the improvements they would most like to see to help meet your needs as a family carer, to help you manage caring for someone with dementia?**

The responses were very similar in nature to the previous question. There were, however, a range of responses that were categorised as follows: -

# Adult Care

## Putting the carer first, recognition, understanding, valuing and respecting the carer (26)

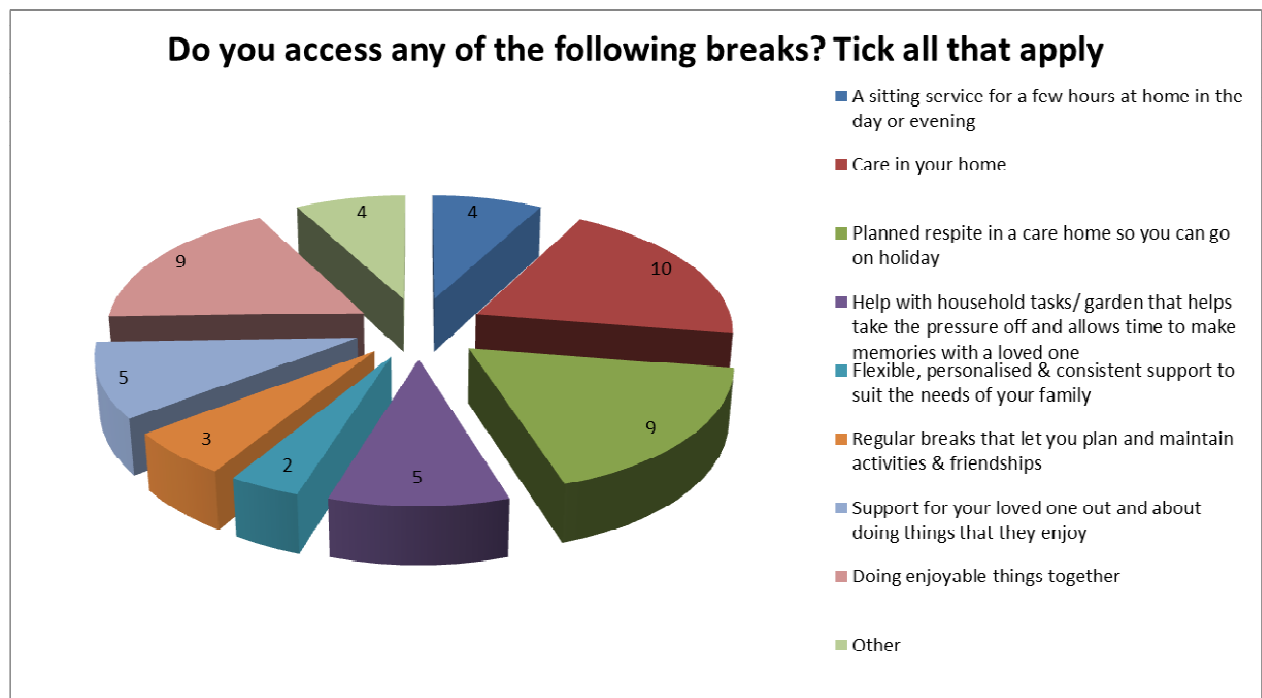
"I have been very happy with LCC Carers team. I know I can phone for advice or a chat when I feel things are getting on top of me."

"One person we could relate to throughout the time we are caring."

"Give the carer greater priority in the process - this is the person who does all the work and has to relinquish their own interests, needs and social life."

"More support when carer needs to go for hospital appointments."

The survey then went on to ask respondents if they accessed any of the following short breaks (results illustrated in the pie chart below): -



44

The small number and nature of the respondents made it hard to gauge what people found most helpful. People completing the survey were asked to state if they had had any problems accessing breaks. 10 respondents stated that they had little or no awareness of the breaks available. Listed below are some statements written about this: -

# Adult Care

*"Is this a joke question? My mother passed away last year but I was never made aware of the availability of any of the above."*

*"These may be available but I do not know how to access them without reading through a large number of leaflets and trying to find out about them."*

*"Wouldn't know where to go to find out."*

There were 3 responses stating that they were unable to access planned respite care: -

*"Yes! Working full time while caring for my husband I needed to plan respite breaks in advance. Local homes do not necessarily have beds that can be booked ahead. I was also fortunate to have a support group that offered social activities and support for me and my husband when he was able to participate. This doesn't happen across the whole of the county."*

45

# Adult Care

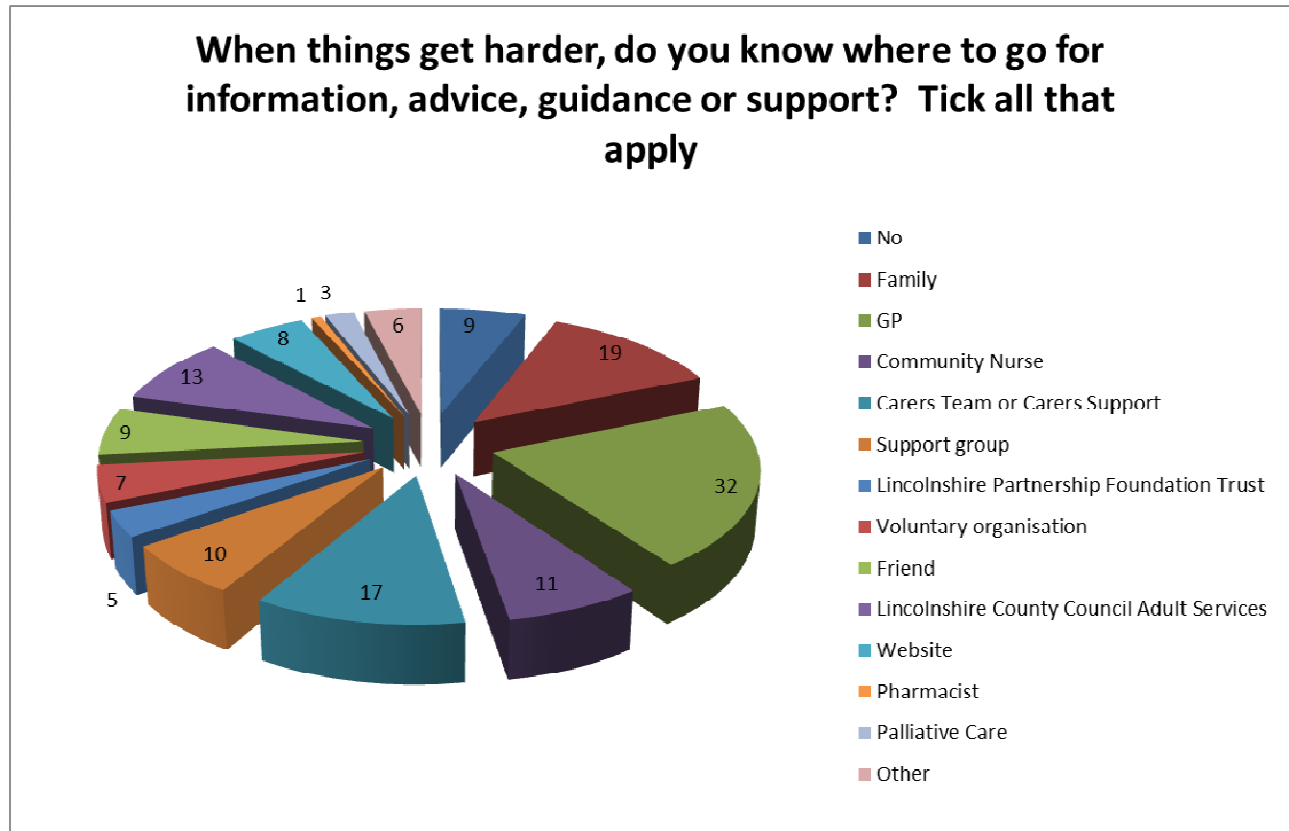
## Phase 5

- Managing at more difficult times, including if possible to live at home

Phase 5 of the dementia journey is concerned with how people manage as the disease progresses and things start to become more difficult. The emphasis is on enabling people to stay at home longer and so the range of services and assistance people can access becomes ever more crucial.

The first question the survey asked in this phase was: -When things get harder, do you know where to go for information, advice, guidance or support?

The responses are illustrated below: -



46

Support groups named were: -

Dementia Support South Lincs      6

# Adult Care

Alzheimers Society 2

Voluntary organisations named were: -

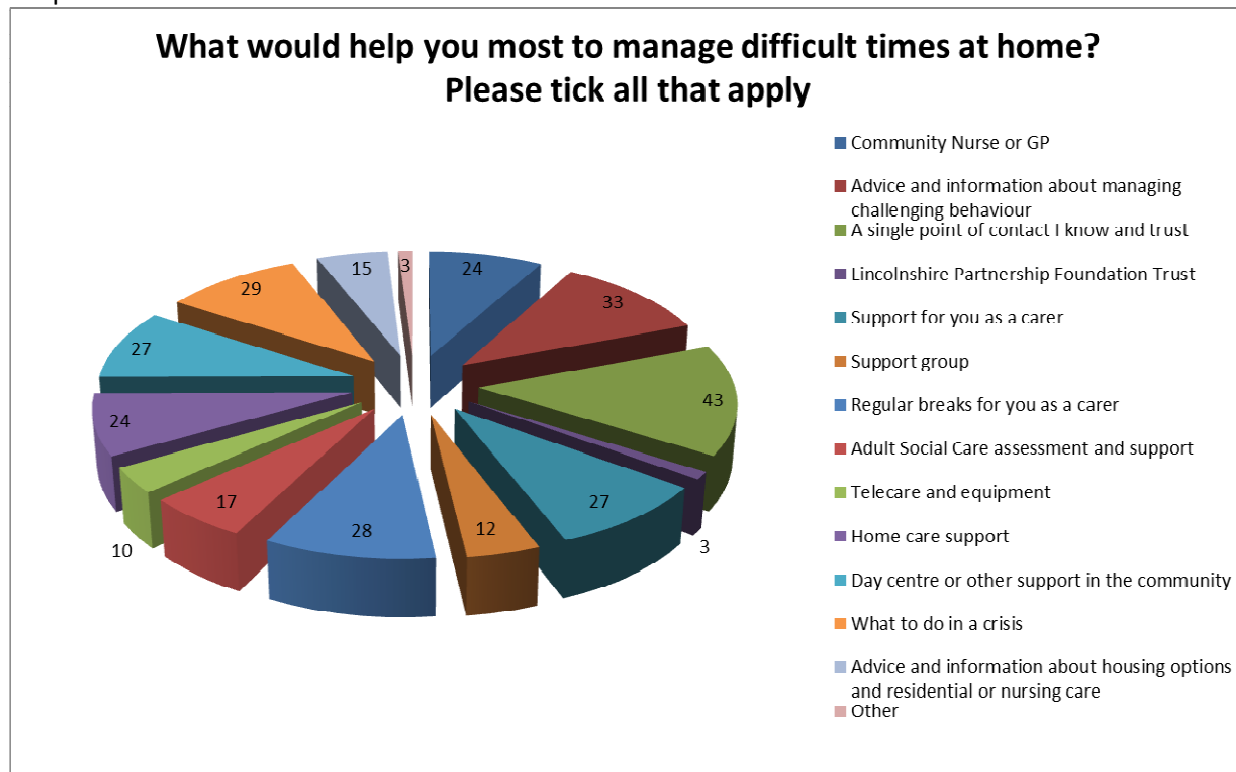
Alzheimers Society 4  
Age UK 1

Websites named were: -

Google 2  
Alzheimers Society 2

Other places included NHS, family members and the Lincolnshire Carers partnership.

The consultation then went on to ask - What would help you most to manage difficult times at home?  
Responses are shown below.



47

The largest numbers of ticked responses were for a single point of contact, advice and information about managing challenging behaviour, support for the carer, regular breaks and day centres to be readily available.

# Adult Care

The survey went on to ask what support for you as a carer specifically would help. The responses were limited to 11 but categorised as follows: -

## **Someone to talk to**

*"Being able to talk to someone knowledgeable - e.g. contact at the Carers' Team, where I felt very much supported, and through my local support group."*

*"Someone to listen who understands"*

*"Regular contact with someone who can help and give advice and assistance."*

*"Someone either in person or at the end of the phone to talk to about challenges and problems."*

## **The needs of the carer taken into account, valued and recognised including carers assessments**

*"Carers needs not met, expected to carry on no matter what...emotional difficulties not considered by adult social care."*

48

*"When caring for a bed bound patient, even the most simple tasks are difficult such as shopping or going to the dentist. I was not made aware of any help mentioned in this survey."*

*"A carer's assessment."*

*"Looking out for the needs of the carer. Planning to give the carer a break once the difficult time has been resolved. A Care Plan that incorporates the patient and carer(s) needs that spans good times and difficult times - flexible. A day centre that is available 7 days a week as the carer is likely to want to go out on a Saturday or Sunday, Bank Holiday etc. Information and advice about what are likely to be the difficult times and how to deal with them ahead of the difficult time."*

*"The front doors to services recognising and respecting carers value, that they do not have to do this, that where the cared for lacks capacity in a certain area the carer is the key decision maker (albeit not the only decision maker). Ease in accessing services as a carer of a person who lacks capacity in several areas of their life. Better support from employer, understanding the responsibility and complexity in the life of a carer. Recognition that information and advice is helpful, like that offered by carers team, but very frustrating if you cannot get round the organisational barriers to apply it!"*



# Adult Care

## Support

*"Support so you can continue working"*

## Voluntary Organisations

*"Dementia Support South Lincs"*

When asked to name the support groups they thought helpful, they responded as follows: -

Dementia South Lincs	4
Alzheimers Society	1

## Narrative responses to the question - What is most important to you about care in hospital for a patient with dementia?

The comments were categorised as follows: - with the category with the most responses coming first and so on. (The numbers of responses under each category are shown in brackets)

### **Listening to and respecting the wishes of the patient, the patient's family and their carer. Treating the patient and their family with dignity and respect (57)**

49

*"People with dementia given time to express themselves and be listened to by medical staff."*

*"Respect shown for the individual even though they have dementia and that they are not discussed as if they are not there."*

*"That their needs are understood in terms of the illness, but that they are also still seen as an individual - i.e. facts for them, not assumptions or generalisation."*

*"Talking with the dementia patient and explained what is going on - even though they may not know what it is that is being said they are aware that something is not right - giving them the option to understand is important."*

*"Appreciation that carer(s) have special knowledge of how to care for the patient, and the severity or not of the individual's particular condition. Patients with dementia covers a huge spectrum."*

*"Nurses, doctors and other staff having the skills to discuss treatment, condition with a person with dementia - very rarely does a person lack capacity in all areas of their life, they retain some insight and*

*understanding and can be engaged at some level in their treatment and discussions regarding their condition. Often staff engage the carer/family only in these discussions."*

## **Enough staff with enough time to provide care for patients (23)**

*"Care - Enough staff to provide proper care to ensure patients eat and drink, are not left in soiled beds and are not discharged with bedsores. Ensure they are clean and smell nice. Allow a hairdresser to visit the ward. Employ staff who are able to treat patients with dignity, respect and understanding. Employ staff who can read patients notes so they are aware if there is a diagnosis of dementia. Allowing carers more visiting time and to let them help care. Listen to carers who know the patient the best...."*

*"Dad was not able to communicate when he was admitted and slept a lot so when I went in the evenings he was dying of thirst and I took yoghurts and rice pudding in case he hadn't eaten. Or asked the person in the next bed if he had eaten. They did not realise he had sepsis in his bladder until we pointed out his tummy was very bloated, despite his skeletal appearance in general. If he hadn't had relatives who could visit daily he would probably have died through lack of care."*

*"Making sure that the patient is fed and not having the food left at the edge of the bed and then taken away before anybody has found out why it has been left. No help provided to feed patient."*

50

## **Early discharge where appropriate and continuation of services (12)**

*"Working hard to ensure discharge at the earliest opportunity."*

*"Not keeping patients in hospital needlessly. The current system of not allowing them home until they are "well" doesn't work because they do not get better. Ensuring services are in place by not waiting until the discharge date to start assessments and don't just so the assessment with the patient who can't always remember what they can and cannot do."*

*"Discharge planning - options available and support with discharge"*

## **Training on dementia for hospital staff (13)**

*"Understanding of the dementia and how it affects the individual and the anxiety caused by admission to hospital and change of routine and unfamiliar surroundings."*

*"Understanding of the condition by nurses and doctors. When mum was last in hospital the doctor was asking her questions she didn't understand and taking her yes/no response as genuine."*

# Adult Care

## **The environment to be dementia friendly (13)**

*"Wards being secure so patients can't go wandering off the ward."*

*"Better design of wards with colour schemes/signage to assist with orientation."*

*"Helpful environment - lockable cupboards help with understanding what is happening."*

## **Identifying the person has dementia (13)**

*"Identifying the patient as having dementia so all staff are aware."*

*"Ensuring diagnosis is passed on to social care if needed on discharge with abilities."*

# Adult Care

## Phase 6

- Receiving care, compassion, and support at the end of life

Phase 6 is concerned about the end of life and ensuring that people with dementia, their families and carers all receive care, compassion and support. This is a very sensitive subject reflected in the responses.

### **Narrative responses to the question - What is most important to you about making decisions around end of life care?**

The comments were categorised as follows: - with the category with the most responses coming first and so on. (The numbers of responses under each category are shown in brackets)

#### **Listening to and respecting the wishes of the patient, the family and the carer. Ensuring that dignity is maintained (31)**

*"Making sure that everything that is important to the dementia sufferer is not only done but seen to be done for the family's sake."*

*"Supporting families to put wishes into effect with adequate support from both health and social care."*

*"Where a person is unable to communicate their wishes, family being involved and respected."*

*"Knowing that I am dealing with matters in the way my wife would have wanted in good health."*

*"Ensuring wishes and requests are honoured."*

#### **Being able to be in the location desired at the end of life and to be with loved ones (29)**

*"Patients allowed home to be in familiar surroundings with their loved ones."*

*"Having family round me and knowing they will be involved in decisions and decisions are not just made by the professionals."*

*"Being able to choose where to die: home, hospice etc."*

*"Being surrounded by loved ones in their own home is my top priority for my husband."*

52

## **Early planning for this stage whilst the person with dementia has the capacity to make decisions**

*"As the person has dementia and as a result of this debilitating issue that is only able to be ameliorated by medication and has no cure, end of life is taken care of by Lasting Power of Attorney. The addition of a non-resuscitation document may also be necessary if other health issues become advanced."*

*"Hard as it may seem - making the plan early, so the person can be involved in the process."*

*"Advance care planning- peace of mind that you will receive the care you have requested and that your family will have the financial support they need."*

*"Taking the patient's wishes into account. Advance care planning for them and for family or friend careers."*

## **Guidance and information to enable the person with dementia and their family to plan (25)**

*"Being told how the disease is likely to progress at the beginning so long term plans can be made whilst the person still has mental capacity to decide what they wish to happen."*

*"Being informed of availability of services (not what should be available but what actually is)."*

53

## **No unnecessary suffering (12)**

*"Regulating care to manage symptoms, not putting patient through unnecessary exploratory operations etc."*

*"Good pain relief and being comfortable."*

## **Finances in order (2)**

*"Knowing finances are in place / loved ones catered for."*

The consultation went on to ask if the respondents were aware of, "The Patient's Journey" an end of Life Care Pathway. Of the 67 who responded, 19 said that they were aware and 48 said they were not.

# Adult Care

## **Narrative responses to the question - What is most important to you as the carer of a loved one at the end of their life, to help you manage?**

The comments were categorised as follows: - with the category with the most responses coming first and so on. (The numbers of responses under each category are shown in brackets)

### **On-going help and support for the carer during and after the end of the person with dementia's life (30)**

*"That the carer has support AFTERWARDS. The sudden end of the caring role leaves a huge void!"*

*"Knowing my loved ones wishes are listened to and followed through."*

*"Support to be able to maintain social life with friends, clubs during the time of being a carer. This will mean that the carer can continue with their life and won't experience such a gap or have to re-establish social networks. (This is something that my Mother often talks about that she wants)"*

### **The place and the manner of the patients death is in keeping with their wishes (24)**

*"That the person I care for has a 'good' death - i.e. in a comfortable non-clinical environment."*

*"Knowing my grandma was a proud woman and died in her own home and was clean and looked after by us."*

*"Knowing that everything has been done in the last question, knowing the way your loved one has been treated meets your expectations."*

### **Dignity and respect are upheld, the person with dementia and their family are consulted (12)**

*"For the carer to be kept informed at all times."*

*"Knowing that they were treated with dignity and respect."*

### **Advice and Information (12)**

*"That I have support and advice on the practical things I have to do."*

*"Information on what to do next."*

54

# Adult Care

## **No suffering for the patient (8)**

*"Being able to make the patient as comfortable as possible."*

55

# Adult Care

## b) Responses from LPFT/Carers/Lincolnshire Residents Groups

As mentioned in the profile of respondents section, there were a number of further questionnaires that were submitted in hard copy form in a different format from 3 different groups, 44 by health and social care professionals working in mental health services, 5 carers and service users and 19 Lincolnshire residents with no declared interest in dementia.

The questions asked of the above group were very much more experiential than those asked on the online questionnaire which invited much more comment and suggestion.

In each case respondents were asked to state whether they agree, disagree or do not know. In all cases the "do not know" responses were discounted. It should be noted that our respondents across these three groups were asked to answer from the point of view of the carer

"I think dementia is generally better understood by the community as a whole than it was 3 or 4 years ago"

	Agree	Disagree
LPFT Group	25	12
Carers Group	4	0
Other Lincolnshire residents	15	1

56

"If Someone I help to look after shows signs of memory problems I know what services to approach for advice, guidance or help"

	Agree	Disagree
LPFT Group	40	3
Carers Group	4	0
Other Lincolnshire residents	16	3

"Professionals such as doctors, nurses, social workers are understanding and helpful when asked for advice about dementia."

	Agree	Disagree
LPFT Group	37	5
Carers Group	2	0
Other Lincolnshire residents	12	1



# Adult Care

"Professionals make clear the need for a diagnosis to determine whether someone has dementia or not"

	Agree	Disagree
LPFT Group	35	6
Carers Group	3	0
Other Lincolnshire residents	12	1

"When someone is diagnosed with dementia, they are given information on other services and told what options may be available."

	Agree	Disagree
LPFT Group	31	6
Carers Group	3	1
Other Lincolnshire residents	16	0

"People who have dementia and ask for help usually receive it."

	Agree	Disagree
LPFT Group	28	10
Carers Group	3	1
Other Lincolnshire residents	8	6

57

"If someone is diagnosed with dementia their close family members are told about support services to help the family manage the situation."

	Agree	Disagree
LPFT Group	27	9
Carers Group	3	1
Other Lincolnshire residents	12	1

"People with dementia get help to stay in their own homes as long as possible."

	Agree	Disagree
LPFT Group	32	7
Carers Group	4	0
Other Lincolnshire residents	12	0

# Adult Care

"People with dementia who qualify for social services (Adult Care) support are usually offered a personal budget."

	Agree	Disagree
LPFT Group	11	8
Carers Group	3	0
Other Lincolnshire residents	3	1

"Carers and family members get support (including training) when they need it, and as long as they need it to help keep someone with dementia safe and well."

	Agree	Disagree
LPFT Group	14	16
Carers Group	1	0
Other Lincolnshire residents	3	5

"Care services for people who live at home are generally of good quality and respect people's preferences and choices."

	Agree	Disagree
LPFT Group	19	14
Carers Group	2	0
Other Lincolnshire residents	3	2

58

"People with dementia who live in a care home are generally supported well by staff who understand dementia."

	Agree	Disagree
LPFT Group	15	15
Carers Group	1	0
Other Lincolnshire residents	8	6

"Doctors, nurses and other health care staff have the knowledge, skills and right attitudes to understand dementia and to help effectively."

	Agree	Disagree
LPFT Group	29	10
Carers Group	2	0
Other Lincolnshire residents	14	2

# Adult Care

"When People with dementia are admitted to hospital the staff there understand their needs."

	Agree	Disagree
LPFT Group	21	17
Carers Group	1	2
Other Lincolnshire residents	9	5

"Advice and guidance on suitable housing for people with dementia is generally available."

	Agree	Disagree
LPFT Group	14	16
Carers Group	1	1
Other Lincolnshire residents	7	3

"People with dementia and their carers get good advice on legal matters such as making a will, handling money and running a bank account."

	Agree	Disagree
LPFT Group	12	12
Carers Group	0	1
Other Lincolnshire residents	8	2

59

"When people with dementia near the end of their lives they, and their families, are supported with compassion, and their wishes and choices are respected."

	Agree	Disagree
LPFT Group	23	8
Carers Group	2	0
Other Lincolnshire residents	8	2

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