



*Evaluation of
Connecting Care in Wakefield*

CARERS' EXPERIENCES OF CONNECTING CARE

healthwatch
Wakefield



CONTENTS

	<u>Page</u>
1. INTRODUCTION	3
2. OVERALL DESIGN, METHOD AND APPROACH	4
3. FINDINGS	7
Theme One - What are the carers and their lives like?	9
Theme Two - The impact of caring	11
Theme Three - Carers' experience of, and view on, the care and support received	15
4. DISCUSSION AND IMPLICATIONS OF FINDINGS	27
5. RECOMMENDATIONS	35

Appendix One Copy of the carers semi-structured interview proforma

Appendix Two Charts showing details of carers interviewed

1. INTRODUCTION

This report details the findings from an independent evaluation of carers' experience of the impact of Connecting Care (CC) in Wakefield; based on 53 one to one interviews with unpaid carers.

The evaluation forms part of a wider independent evaluation of Connecting Care (formerly known as Care Closer to Home), being conducted by Niche Health and Social Care Consulting (Niche) and supported by Healthwatch Wakefield. Niche is an independent organisation which undertakes consultancy support, including external evaluation of complex transformational projects, across health and social care. Healthwatch Wakefield is an independent consumer champion, set up to help people get the best out of health and social care services and to make sure that the views of the public and people who use those services are taken into account in both improving and shaping them.

The Connecting Care teams include:

- Community Matrons
- Physiotherapists
- Occupational Therapists
- Social Care staff
- Age UK workers
- Carers Wakefield workers
- Pharmacist

Helping and supporting carers is a key aim of the Connecting Care approach. Specifically the aim of:

- carers being supported and prepared to care for longer.

We were therefore asked to carry out interviews with unpaid carers of people who have received services from Connecting Care staff in order to answer the following question:

- what is the impact of Connecting Care (CC) on the quality and experience of services for both patients and their carers, in the opinion of carers of people directly receiving services as patients?

As well as answering the research question above and providing findings and case studies of interest and value to the staff commissioning and providing services in Wakefield, we would hope that many of our findings will be of interest to counterparts in other areas.

2. OVERALL DESIGN, METHOD AND APPROACH

At the outset we proposed to conduct around 50 face to face interviews with carers about their experiences of the Connecting Care services. We defined carers, for these purposes as:

- people who are receiving services from Connecting Care teams, and who also self-identify as a carer of another person receiving services from a Connecting Care team;
- people who are known to a Connecting Care team and to Carers Wakefield, but who are not personally receiving any other services from Connecting Care;
- people identified as carers via the patient interviews, but not otherwise known to services at all.

Niche and Healthwatch worked together to agree the framework of questions to be asked. The resulting 14 question qualitative semi-structured interview schedule was approved by the Connecting Care evaluation steering group and piloted on five carers. After making some minor amendments, we proceeded with the full evaluation. A copy of the interview proforma is included at appendix one.

Our sample

We planned to obtain as large a sample as possible (around 200) so that we could randomly select from the names put forward, following Connecting Care staff gaining their consent to share their contact details with us.

It was agreed with Connecting Care service managers that we would obtain carers' details (name and contact details) from three sources:

- Carers Wakefield staff
- Connecting Care staff
- Healthwatch staff (who were concurrently conducting face to face interviews with service users during which they often had contact with carers).

The staff who obtained the carer's details were also responsible for obtaining consent from each carer (to share contact details with Healthwatch) and explaining why they were being asked to participate in a carer's interview. It was anticipated that we would select equal numbers from each source. In reality, referrals from Connecting Care staff were slow to come through. It was not just a case of getting a signature to consent to being approached by Healthwatch at initial assessment (which was a process set up for service users). This would quite possibly have given us carers with a lot of experience of caring, but not necessarily a lot of experience of Connecting Care support. It was necessary for both Connecting Care and Carers Wakefield to pro-actively contact carers and ask for their permission to pass on their details to us so that we could contact them. This took time for Connecting Care and Carers Wakefield to do and was an additional duty for them.

In addition there were some practical difficulties due to the lack of a shared patient/service user record, meaning that carers' contact details might only be known to one of the services involved. In some cases, carers' details were not recorded at all. It was therefore, extremely fortunate that Healthwatch were concurrently undertaking a large review of service users and that this (which again had faced ongoing issues in gaining details of consented service users) was much farther forward and was able to be used as an excellent source for recruiting carers.

In the end we sourced referrals as follows:

Source	Number referred
Carers Wakefield staff	13
Healthwatch via patient/service user interviews	37
Healthwatch via other source	3

As the process of receiving referrals took so long to put into place we had to accept and interview all carers whose details were provided to us, except for two who subsequently cancelled due to ill health.

Governance

The survey processes and approach were overseen and signed off by the Connecting Care evaluation steering group, which consisted of representatives from Wakefield MBC Public Health (who commissioned this piece of work), Wakefield CCG, Healthwatch Wakefield, Mid Yorkshire Hospitals NHS Trust, Age UK, Carers Wakefield and Niche Health and Social Care Consulting.

Contact and consent

Contact processes differed slightly, depending on the source of the consented carer. Some carers had already met the Healthwatch interviewer when she came to carry out an interview with the patient/service user. However, all consented carers were either phoned or spoken to directly to explain or confirm the purpose of the interviews, ask if they were still happy to be involved, answer any questions they might have about the interview process and to agree a date, time and venue for the interview. They were then told the name of the people who would be interviewing them and this was confirmed in writing.

We offered to meet carers at a venue of their choice. Interviews were carried out by two interviewees, one employed by Healthwatch Wakefield, and one by Niche. This enabled one person to conduct the interview whilst the other took notes, alternating between interviews, and enabled ongoing confirmatory discussion of the themes arising. The same Healthwatch interviewer was used for the face to face interviews throughout. The same Niche interviewer was used for all but four interviews when she was unavailable and replaced by a Niche colleague for two interviews and a different Healthwatch colleague for two further interviews. Niche staff analysed the findings and pulled together the findings and conclusions detailed in this report.

All interviews were carried out face to face in the carer's or service user's own homes except for two which were conducted by phone (as the carers involved lived in Scotland and London). The length of interview varied from around 25 minutes to an hour. In total we spoke with 53 carers between July 2015 and April 2016.

On arrival for the interview, following introductions, the interviewers:

- explained once again (verbally) the purpose of the interviews
- explained that carers could withdraw from the process at any stage
- explained that we were independent from the services we would be discussing, but would be feeding anonymised views back to those services
- explained how the process would work
- read out loud a written consent form which they asked the carer to sign (in one instance the carer was illiterate but agreed we could sign on his behalf)

- upon completion of the interview, left a FAQ (frequently asked questions) sheet containing answers to questions plus name and contact details should they have any future questions.

The interviewers took time to put carers at their ease and to make it clear that they really were interested in them. Some interviews were very emotional – just talking about the difficulties and stresses that they had faced was hard for some. Some became tearful in taking. A considerable number thanked the interviewers for coming to meet them and for listening to them. The interviewers always left a contact name and details for the Healthwatch lead, in case they had any queries following the interview. They also left everyone with a leaflet about the health advice line, provided by the Wakefield Citizens Advice Bureau (CAB).

If, during the interview it became obvious that a carer was not aware of the services that Age UK and Carers Wakefield could offer, and it was clear that they might benefit from them, then they were advised about these at the end of the interview and offered the opportunity to receive further information about them or for a direct referral to be made.

Ultimately, we were able to recruit a wide range of carers, from across the whole of the Wakefield District, who were able to share a vast range of experiences and insights. We are extremely grateful to them for taking the time to talk with us.

**** All names included in this report have been changed. Where we have provided a more detailed case study we have received approval from the carer involved to do this.***

3. FINDINGS

We have structured this section into two parts. The first part provides some description about the carers whom we met – some facts and figures and details about what their caring role included. The second part details the themes which emerged from our interviews, drawn together into three overarching themes:

- **Theme one** details what the carers told us about what their lives are like. This covers areas such as, the support they receive from their family, findings around their own health and that of the person (or people) they are, or were, looking after.
- **Theme two** describes the impact of caring on the carers. This includes the impact on their own physical and mental health and on their finances. It also looks at the impact on social isolation and loneliness.
- **Theme three** focuses on the help and support which carers have received from Connecting Care staff (and where relevant from other sources) and captures their views on how easy they found it to access and use that help, what they found useful and their views on what other support would have helped them in their caring role.

Where possible, we have used the carer's own words to describe what they told us.

Some facts and figures about the carers we interviewed

We interviewed 53 carers:

- two thirds of them were women;
- 79% of them lived with the person they cared for;
- most were spouses (61%) or children (24%) of the person they were caring for;
- the majority were over 60 years of age with 9% of carers in their eighties and
- all, but two, defined themselves as White British
- all, but three, lived in Wakefield district
- 43% were in Bullenshaw Hub area, 43% in Waterton Hub area, 6% in Civic Centre Hub area (with the remainder outside Wakefield district)
- four were in paid employment.

For more detail see the charts in appendix two.

The most common tasks that carers were undertaking were:

- housework including shopping, cleaning and laundry
- food preparation including helping service user to eat in some cases
- helping with toileting (and dealing with incontinence)
- ensuring medication was taken correctly
- helping the person they cared for to get into and out of bed
- helping with washing/personal hygiene/showering and getting dressed/undressed
- helping with mobility e.g. helping them to get around with wheelchair, or mobility aid
- taking the person to hospital and other appointments
- managing finances
- managing the person's safety e.g. helping with re-positioning, making sure doors and windows locked, ensuring the person did not fall or picking them up when they did
- organising the person's care and services

- re-assuring the service user and dealing with memory problems or other mental health problems such as anxiety.

What carers said about what they do

John's (68 years) wife has a bowel condition and told us "... I used to work full time and had never done house work before, but now I do everything.....M (his wife) has recurrent diarrhoea so I have to boil wash everything which is a burden.."

Mandy (55 years) who lives with her mother, who has dementia said "...I feed mum which can take up to one hour each meal..."

Sharon's (64 years) husband Adrian has severe arthritis with many fused joints and had a stroke about a year ago. Since then she has to help him to get dressed including putting his shoes and socks on. She has to clean up after he has been to the toilet. She has to go into the shower with him to help him which is difficult. She does all of the housework and cooking.

Bob's (63 years) mother has dementia, but lives alone. He told us "...It is a 24/7 job. I go over to see her twice a day and stay for quite a while. I organise all her shopping, meals, finances, washing, medication etc. I take around 30 phone calls from her each day. I sort out all her medical care and take her to hospital appointments, which can last all day long. She comes over to me all day on a Friday and one of my daughters has her over on a Sunday for the day.."
Irene (56 years) said "... I do everything for him. By 9pm I have had enough and just go to bed..."

Themes arising from the interviews

Theme one - What are the carers and their lives like?

Family support for carers

Many carers that we spoke to were also being supported by other family members. Many had family who lived locally and provided help with practical tasks such as shopping, cooking meals and running errands. In addition they sometimes provided respite so that the primary carer could get out. They told us that this was often the difference between coping and not coping, although it was still hard for them. 14 of the 53 carers interviewed had significant extra support from other family members with visits from them up to several times a day. Others had family or friends who supported them at least a couple of times a week.

What carers said about the support they got from family members

Norma (72 years) said “..my son takes my husband out every week twice weekly even if only for a couple of hours so I can get some respite, I can then do my shopping, this is my time and I need this..”

Alf (88 years) said “..my family do the big shopping, gardening, change beds and help with ironing. We couldn't manage without them..”

Dora (73 years) said “..my daughter or grand daughter visit every day and often bring meals or can run errands.... without my daughters I could not cope..”

Brenda (82 years) told us “..my daughter works full time but lives locally and helps me to look after him..”

Anne (60 years) said “..my son and daughter came several times every day but I don't think even they realised how hard it was. She was awake nearly every hour in the night and I was exhausted...”

Gloria (50 years) said “..we looked after Dad between us – my two sisters, my niece and me..”

Jackie (47 years) “..my brother comes twice a week to sit with them (her elderly disabled parents) so I can get out to do the shopping...”

Reluctance to want or accept help

Some carers told us that they had been offered help, either for themselves or for the person they cared for, but had chosen not to accept it. This had sometimes had a negative effect on them (as their health subsequently suffered due to their caring role) and some said that, in hindsight, they wished they had accepted it. In some cases the person they cared for had rejected help, which could be very frustrating for the carer.

A few carers said that they did not want strangers coming into their house and would “.. prefer to struggle on...”. Sometimes we could see that they really were struggling. Some carers did not want help for themselves as they did not want to talk about their situation with others, whether or not they were in the same position, saying it would be “too depressing”.

Carers' health

Many of the carers that we interviewed were themselves in poor health, even without taking into account the impact of their caring role on their health (which for most was significant and is discussed in more detail below). This is perhaps not unexpected, given the age profile of carers. The level/severity of the health problems with which some carers themselves were coping was significant. Despite these they were struggling on, often with quite limited (or no) help. In some cases it was difficult to establish who the carer was, as both carer and service user relied very heavily on each other.

Carers who had significant health needs of their own included:

- Madge (78 years) has spondylosis and arthritis and can hardly walk and yet does everything for her husband who spends most of his time in bed.
- Paul (66 years) was an amputee himself and cares for his wife who also needs a wheelchair when outside the house.
- Jackie (51 years) is registered disabled with a crumbling spine and sometimes has to use a wheelchair. She cared for her diabetic, blind, amputee husband at home until his death from cancer.
- Dora is a 67 year old lady with a chronic lung condition and tremors who has been unable to work for many years due to ill health. She looks after her 92 year old mother.
- Both Ada (84 years) and her 93 year old husband use mobility scooters.
- Linda (65 years) has MS and is able to stand for only short periods herself and can walk just short distances. She cared for her terminally ill, incontinent husband more or less single handedly during the last few months of his life.
- Bill (75 years), is diabetic and on insulin, has been diagnosed with asbestosis and other complaints which are age related. He can't see very well, cannot write well and states he cannot manage without his wife (the service user.) He says "*..we work as a team..*"

Some carers told us that there was sometimes little consideration given to their own health needs by the services which were supporting their loved one.

What carers said about the consideration given to their own health difficulties

Linda (65 years) told us "...because of my MS even simple things are difficult for me like putting my shoes on. One day I was told they needed a urine sample from my husband. They told me to go the GP to get the right bottle. Then I had to come back and get the sample. Then I had to go to the GP again. Then the same day they asked me to come and get a prescription and get it made up for him. Each trip was like a marathon for me. I was exhausted. There was no consideration for my health problems at all. The worst was all the washing and changing the beds often several times a day due to ongoing leaking of the catheter..."

Jackie (51 years) said "...there was no consideration for my health and disability. It has definitely had an impact on my health. And it has screwed my son's head up seeing his father suffer so much without help..."

Bill (65 years) has a problem with his hand and needs an operation on it but he can't have an operation because he would not be able to push the wheelchair or look after his wife. He told us that his knees are "*going*" because his wife is mainly in bed and he goes up and down stairs at least 20 times a day. He is tired all the time.

Looking after service users whose health was declining

The service users whom carers were looking after, or had looked after, had a wide range of needs,

often having complex and multiple diseases and disabilities. In a number of instances, the Healthwatch interviewer had previously interviewed the service user (as part of the service user survey which is also informing the overall Connecting Care evaluation). She commented on how their health had deteriorated and how their needs had increased even during a relatively short period of a few months.

Some carers found it difficult to understand why, given the expected trajectory of deterioration and decline (e.g. where they cared for people with terminal or long term conditions), some services had just visited them a couple of times and then left them to cope.

- one lady (in her late seventies) caring for her terminally ill husband had been discharged by the Macmillan service just months before his death and told to “ring them if she had any concerns”
- several carers had struggled to get services for their relative with deteriorating dementia
- several carers were worried that they had no plan in place to deal with an emergency, particularly if anything happened to them
- some lamented the lack of ongoing support such as that which the community matron service had provided in the past.

For several people

Eight of the carers we interviewed were looking after several people, not just one. This comprised:

- sister and brother with dementia
- mother, mother-in-law and wife
- husband and man next door
- friend and neighbour
- both parents
- wife with multiple problems and disabilities and son with Multiple Sclerosis
- husband with heart disease and grandson with mental health issues
- wife and brother with mental health/alcohol issues

Theme two - The impact of caring

The impact of being a carer on the carer's own health

Even with excellent support almost all carers report that their caring responsibilities had had a huge impact on their own mental and physical health. Just eight of the 53 carers interviewed told us that they felt that their health had **not** been affected by their caring role. Many described the physical impacts of caring, such as torn muscles, bad backs, worsening eczema and joint pain. Some examples of such situations are shown below.

- Marie (aged 78 years) had a hip operation last year, before her (terminally ill) husband became ill. She was making a really good recovery and was getting out and about. However, caring for her husband and lifting him so much had left her with a torn muscle in her leg/hip and she now walks with a Zimmer frame, has very limited mobility and is in constant pain.
- Elsie (aged 84 years) looks after her husband who is 93. She told us that helping him onto the toilet, and picking him up from the floor when he fell, had made her bad hip a lot worse.

By far the biggest impact was on carers' mental and emotional health. Many carers told us they were exhausted, shattered and tired all the time. A number were in tears as they discussed this. Although we didn't ask specifically, ten carers chose to tell us that they had had to go onto anti-depressants "to cope". They felt exhausted by the relentlessness of their role as a carer. In a significant number of cases they also felt that their mental health had been affected by the difficulties and obstacles they had faced when they first tried to get help and did not know where to go, or were refused help when they felt they desperately needed it. Several said that they had had to put their own lives on hold.

Carers told us that they were frequently irritable and often felt down as a result of their caring role, and a number were very tearful when speaking about being a carer. One carer told us he was self-medicating using alcohol, and one was self-harming.

Phrases we heard over and over again, included *"..tired all the time..."* *"..I am shattered..."* *"..on edge and snappy"* *"..tearful.."* *"..I am just frustrated and short tempered all the time ."* *"..I have good and bad days.."* One carer said *"..some days I could go out and not come back.."*

What carers said about the impact of caring on their own health

Anne (64 years) told us: *"...I was exhausted, in tears a lot of the time and had to go on anti-depressants, looking after Mum with severe dementia. When I needed a cry I could go up to my son's house.....sometimes I would go upstairs for a cry so I did not upset the grandkids. You don't realise what you are taking on or how hard it is. That's why I had to go on the anti-depressants. It was the mental side that got to me. It was so hard. No one knew how hard it was..."*

Peter (66 years) said he had never admitted it to anyone but his health has suffered. He feels stressed and tense all the time and can't relax. He is always waiting for the next phone call. *"...If I hadn't retired then I don't know how I could have done this..."*

Deirdre (64 years) At first she said that it had not impacted on her health but then admitted that she does get very tired and on a recent visit to the GP he said that he thought she had depression and put her on anti-depressants. She doesn't sleep well at night.

Claire (59 years) got very upset when we asked if she thought that being a carer had affected her health and said it's really hard to cope with everything- mum, job, teenager and she is shattered.

Steve (53 years) told us that his health and his brother's health have definitely been affected by having to care for his Dad and find out about and organise everything. They both suffered from anxiety as a result and have been put onto medication.

Several carers also told us that they were worried about the future and what would happen to the person they were caring for if anything happened to them. Several carers were concerned that they did not have *".. a backup plan.."* or crisis plan or safety net. *"...What would happen to them if anything happened to me...?"* was a frequently expressed concern. Understandably, carers with significant health problems of their own, or who were much older than the person they cared for seemed to have this as more of a concern, although it was also articulated by some younger carers too.

Others felt guilty that that they were unable to care as well as they felt they should. Or, if they had had to put the person they cared for in a home, they felt a lot of guilt from that too. The

emotional impact of this was often considerable as some also felt resentful about the impact on their own lives and then felt guilty that they felt resentful.

Some carers were clearly trying to protect the person they cared for, and sometimes the rest of the family, from their own emotional distress. We experienced this with several carers who started the interview very upbeat, in front of the person they cared for, but then, when we moved into another room alone, became very tearful and distressed and 'opened their heart' about how hard it all was for them.

What carers said about feeling guilty

Gloria (48 years) said *"the stress was massive; I felt a failure at home because I could not look after my dad and out of all the family I have been the one who has usually taken control. I felt really guilty. I was exhausted. I felt a failure at work..."*

Robert (63 years) said *"...I promised my Dad that I would never put her (Mum) in a home and feel guilty even thinking about it, so just got to plod on..."*

Social isolation and loneliness

Although we did not ask a specific question about loneliness or isolation, it quickly became clear, when speaking about their lives, that many carers were quite isolated and/or felt lonely for much of the time. Many of them were unable to leave the person that they were caring for long periods and often as little as one hour a week.

What carers said about being lonely and isolated

Dora (65 years) speaking of her 92 year old mother who has dementia said *"...I don't dare go out and leave her as there is a chance she will fall down the steps and if she falls down behind the door I would never get in..."*

Brian (72 years) told us *"...It's very difficult to get out as I can't leave A on her own for any amount of time..."*

Margaret (68 years) said *"..the only time I have to myself is when I go to Aldi or Asda.."*

Ron (85 years) told us that he and his wife were very isolated and had no family or friends around

Marie (78 years) *"...my husband spends quite a lot of time in bed as he gets very tired and so I get lonely.."*

Winston (72 years) said *"..I do get lonely. These days people do not speak to each other, It is very lonely for both of us. I can only leave my wife alone when she is asleep early in the morning..."*

Peter (75 years) *"..There is nobody who has come and said how are you coping and how can we make it better? Someone should come and see us just to have a cup of tea now and then.."*

Arlene (60 years) *"...We need someone to listen to us. Sometimes I just need to have a cry it's so bad..."*

Many faced additional practical difficulties in getting out which made them feel quite trapped. Reasons for this included:

- their own poor health and the fact that they felt exhausted and “run down”
- lack of accessible transport,
- expense of having to take taxis,
- limited time to get out in between (paid) carers’ visits
- poorly managed incontinence
- in a couple of instances the service user/patient did not want the carer to go out, because they did not feel safe at home without them.

Poorly managed incontinence stopped a number of people going out due to the practical and embarrassment impact of dealing with leaks in public. One lady (aged 78 years) told us that her husband was incontinent of faeces and has to go to the toilet very urgently. This is not always possible when out and they had had an embarrassing incident when he had soiled a friend’s carpet which has made them reluctant to go out. She has not told anyone about this problem. She explained that at the GP surgery they have notices “all around” which tell you not to introduce extra topics during a GP consultation as they are short of time and so she did not feel she could raise this, leading to increased isolation.

Another, Brenda (82 years), said *“I would love to go out more, but he has had a couple of falls and we worry about his pants/pads leaking, which they have before, leaving him soaking wet in public. He is also incontinent of faeces which is very difficult to deal with...”*

Few people that we spoke to had respite care. Some said that it had been offered but, that because it had to be paid for they were unwilling or unable to take this up. Some had family members who could sit for them so they could go out. Even if they did have some respite from friends or officially they were sad that they had to go out alone and that their partner would not be able to join them, or was unwilling to go out.

For some carers this had been alleviated by services they had received from Carers Wakefield or Age UK.

What carers said about how Carers Wakefield had helped them combat loneliness

Brenda (82yrs) had recently received support from Carers Wakefield and told us several times during our interview how much she was looking forward to going out to a forthcoming carers’ meeting which was going to involve trying out alternative therapies such as Aromatherapy.

Anne (60 years) *“..the lady from Carers Wakefield was not like a support worker she became a friend...”*

Jean (78 years) *“..T from Carers Wakefield is a great support and now a friend...”*

However a lot of those who told us that they felt lonely or isolated were not aware that Carers Wakefield or Age UK could offer a one to one service, but said they would definitely be interested in such a service. Following the interviews (and with carer’s consent in all cases) Healthwatch referred carers to the following services for additional support:

Onward referral to	Number referred
Age UK (Wakefield)	6
Carers Wakefield	8
Other third sector service (City of Sanctuary and Total Voice)	2
Back to another service within Connecting Care	1

Financial impact of caring

In addition to the physical and emotional impact of being a carer, many carers reported financial pressures that had been caused or made worse as a result of being a carer. A number of people had taken early retirement in order to care for a relative (usually a parent) and had had to give up their job because they could not cope with the demands of caring and the demands of their job.

On a positive note, almost all carers were aware of and in receipt of carers' benefits such as attendance allowance. A significant number were also aware of the "My Time" money which was available for carers. Several reported that they had been helped by the Connecting Care social workers or Carers Wakefield and Age UK to claim everything they were entitled to which had really helped them.

Mabel (74 years) has a social worker who got her and her husband a £100 reduction off their rent which had been a great help. *"..the extra money made a real difference to us..."*

Irene (56 years) told us *"...we had big financial problems and J from Carers Wakefield helped us to sort them out..."*

Theme three - Carers' experiences of, and view on, the care and support received

How easy was it for carers to access help and support when they first needed it?

However good the Connecting Care service is, it is no help to people if they are unable to access it. We only spoke to carers of people who were receiving (or had received) services from Connecting Care and it was not always clear how they had been referred into these services. In terms of specific support for carers themselves (from Carers Wakefield) there appeared to be a wide range of routes through to this including:

- referred by Connecting Care staff
- referred by non Connecting Care staff
- self-referral after being given information by Connecting Care staff
- self-referral after seeing information in GP's surgery
- self-referral after seeing information elsewhere e.g. Internet

For many, accessing the help had been straightforward as they were referred by their GP or other source. Twelve carers, however, told us about significant difficulties that they had had to access help or support from services (both for the person they cared for and for themselves) when the need for more assistance first arose. They described a frustrating and often exhausting process to get help. Often people started with their GP or Hospital, but in some cases the carer had approached many services in an attempt to get help, both for the service user and for themselves.

What carers said about accessing help and support when they first needed it

Mabel (74 years) told us *"...After his (her husband's) diagnosis I was given three numbers to ring and told they would sort out everything and they have. We both have marvellous help. I can't believe it.."*

Ada (84 years) said *"...you don't know where to look for help when you start, you are lost at first. I had no idea where to go for information..."*

Helen (73 years) said *"...I just think that when something like this happens that you don't have a clue and you don't get any information. You don't know and don't get given any...."*

Arlene (60 years) said *"...you can't ask a question if you don't know what questions you should be asking....."*

Steve (50 years) said, of trying to get help for his father who had worsening dementia *"..As a carer, you are out there on your own. You have to find out everything for yourself. All the information is separate so you have to go to each separate organisation to find out what they can do. It should all be together in one place. It's not a very efficient way to work...."*

Many carers told us that, they felt, their GP should be the common gateway to the support which they needed. Others, like Patrick (see story below) were put on a "waiting list" to access services, during which time they had struggled to cope.

One carer's story of his struggle to get help and support

Patrick (53 years) lives alone and took early retirement a few years ago, when the chance became available. He is the only child of 85 year old Mary who lives alone on the other side of Wakefield. Last year he became increasingly concerned about Mary's health and safety. She had become progressively frailer, with her mobility getting worse. He discovered that she had not been able to get in the shower for 8 or 9 months as she did not feel safe in there. She had poor eyesight and a number of medical conditions such as diabetes and heart disease. She was struggling to prepare meals and could not get out alone. Patrick was her only living family member. He was driving 10 miles each way to see her each day and to do her meals, shopping and housework but could see that she needed much more help.

He said that "*..despite being very ill and frail she didn't seem to be on anyone's radar...*". He tried to get a wheelchair for his Mum but was told it would take 3 to 6 months for an appointment. He was told that before any other services could be provided Mary would have to be assessed by social services, but that there was a waiting list for this. He was told that the service was working to capacity and basically he would have to wait for someone to die before his mum got allocated anyone. He asked how long they would have to wait but was told that it was policy not to say how long the waiting list was.

Patrick found the phone number for SPOC (community nursing single point of contact) and phoned there, but was told Mary was not on the system as she didn't have a social worker and they couldn't help her. He found the number for Carers Wakefield on the internet, and approached them and they sent him "a pack in the post".

In the meantime his Mum's condition was getting worse. As Mary's son he did not feel it was right to do her private care – such as showering, so he managed to find a private carer who came in to help with meals and to help Mary to have a shower. After a few months a physiotherapist or occupational therapist came to assess Mum. Shortly after this (in early 2016), five months after he first tried to get help for her, Mary died. Patrick got a phone call from Social Services to say she had come to the top of the list for an assessment, and the appointment from the wheelchair service, after her death.

Who would carers turn to for advice or information about the care and support of the person they were caring for?

One of the aims of Connecting Care is to keep people safely in their own homes for longer and so it is clearly an advantage if carers know whom to contact (both in and out of hours) if they have queries or concerns. We were therefore interested to know whether carers knew whom (within the Connecting Care team or outside it) they would turn to for non-emergency information, advice or support either within or outside office hours. As shown below, the most common answer was the GP. Given that these carers are looking after some very frail and vulnerable service users, it is of concern that a considerable minority did not know who they would call or where to go for information either within (20%) and outside (35%) office hours, and that 16% said they would call 999.

Within hours:

- 33% said they would call their GP
- 22% said they would call a member of the Connecting Care team (e.g. Social Worker)
- 20% said they didn't know who they would call

Out of hours people were less certain who they could call.

- 35% said they didn't know who they would call
- 16% would call 999 or an ambulance
- 8% said they would call their GP
- 8% said they had been given a number that they could call out of hours

Carers also told us that, when they had tried to get information and advice about the service user's care, support and treatment that this had sometimes been a difficult process for them. This appeared to be a particular difficulty for carers who did not live with the person that they cared for, although not exclusively so.

This was not just an issue with regard to Connecting Care staff, but also GPs and other community services and hospital services. Some carers had received help with this issue from Connecting Care staff (particularly from Carers Wakefield workers) and therefore we feel it is relevant to include concerns about those other services here too.

Carers told us that:

- services would not always share information with them about the service user citing "data protection" and "confidentiality" even though it was likely to be to the potential detriment of the service user for this not to be shared with them,
- services did not always explain to them what they were doing (for the service user) or why they were doing it – or carers did not understand or remember these explanations,
- services did not always ask carers for their opinion about the service user even though they were with them 24/7 and, for example, where the service user clearly had a mental incapacity such as dementia.

This left carers feeling marginalised and frustrated, and in some cases they felt that this had compromised the safety of the care given to the service user.

It is notable that none of the carers quoted above had received help or support from Carers Wakefield. Some carers who did have a good relationship with a support worker from Carers Wakefield told us that they had received help to write letters or fill forms in to enable them to get the information they needed. A couple of the carers quoted above, went on to get support from Carers Wakefield or Age UK which helped them to overcome these problems by ensuring that they were "registered" as carers on all relevant health and social care records and appropriate permissions or consents were put in place on the patient/service user records to indicate that information could be shared with them. Once this was done, their lives became easier.

What carers said about trying to access information about the care and treatment for the person they were caring for

Lionel (66 years) has insisted that the people who can have access to his wife's records be documented on System 1. This is proving to work well but he had to push for it and it took a lot of time and effort for him to set this up. He said it would have been "*..much better if this had been set up from the start..*"

Debbie (62 years) told us that health and social care professionals don't always ask her opinion even though she knows her neighbour Phyllis (who is in her eighties, has dementia, is registered blind and lives alone), best and is with her for hours every day and does everything for her. For example when the GP visited Phyllis he found her crying and put her on anti-depressants.

Debbie had to contact the GP to tell him that the reason Phyllis was upset was she had just been registered as blind. So he took her off the anti-depressants. But it would have been better if he had spoken to Debbie as part of the assessment, particularly as Phyllis has dementia and can't remember things. GP said he could not discuss Phyllis's care with Debbie as she was not the next of kin. After this incident, however (with the permission of Phyllis) the GP did register Debbie as a person he has permission to talk to.

Janet (57 years) went to see her mother's GP because of concerns about her mother's worsening mental health - including neglecting herself, being violent towards her father and threatening suicide. The GP told her "*..we cannot and will not discuss your mother with you..*"

Irene (56 years) wanted to find out more about her husband's care and condition as she had concerns about it getting worse and wanted to know how this might impact on her as a carer. She made an appointment to speak to the GP and told the receptionist that it was about her husband. She was told this would be OK. However when she got there the GP said that it was not OK to talk to her about her husband "*..behind his back..*" and would not discuss this and so she has been left not knowing who she can ask.

Fiona (48 years) told us that she approached her Mum's GP, as it became obvious that her dementia was getting much worse, but said she was "*..fobbed off..*" because she was not registered as a patient and the GP would not discuss this with her.

What carers said about trying to access information about the care and treatment for the person they were caring for (continued)

Fred (82 years) and his partner Betty care for their neighbour Jerry. They have been friends for a long time, holidaying and socialising together for many years. Jerry has a neurological condition, which affects his mobility and he falls frequently. He has recently been diagnosed with terminal cancer. Fred also has cancer (*"but.. it's under control.."*) and Betty has high blood pressure. They spend most of their time helping and caring for Jerry who lives in the house opposite. They pop in to see him 3 or 4 times, or more, each day. They manage his money and do all his shopping, run errands, help re-position him when he gets uncomfortable, take him to hospital appointments (which can last all day), deal with all services (e.g. the private carers which Betty organised for him), collect his medication, get him drinks, check his curtains and doors are closed at appropriate times etc etc.

Sometimes, when Jerry is well enough, they take him out to the local garden centre. The nurse visits each week but they have no idea what she comes for and she has had no contact with them. They said *"... we have tried to catch her but we don't know when she will come and she's in and out so fast we can't catch her. No one seems to care when you are after a certain age. We are not given a lot of information as we are not family..."* They also told us that Jerry had recently had a raised toilet and mobility rail put in, and said *"..it's good but we don't know who told them to come.."*

When they had concerns about Jerry's deteriorating health they were told, by the carers, who Jerry pays to come in, that they are only neighbours and not allowed to phone the doctor. They do not see themselves as carers, but as friends. Betty said *"..We do it with a good heart and don't want thanking. We just want him to be happy..."*

Co-ordinating the various services and support

Another key aim of Connecting Care is that the experience of care should be co-ordinated and seamless from the service user (and carer)'s point of view. We therefore asked carers what their experience had been of this. It should be noted that a number of them said that few services were involved so there was little for them to co-ordinate or comment upon.

Around a quarter of carers that we spoke to said that the care and support received had been well co-ordinated. Staff who visited them at home worked well together and things were joined up. Sometimes they told us the name of the person who co-ordinated things for them – for example a social worker or Age UK worker.

What carers said about how well co-ordinated services were that they received at home

Norma (72 years), Pat (61 years) said of Connecting Care staff *"..I like the people, they work well together..."*

Kitty (84 years) said *"....they all work well together in my experience. They are based in Bullenshaw and I feel they communicate well with each other..."*

Lionel (66 years) told us that he is very active in ensuring his wife gets the care that she should, but said the services are *"..very good and joined up well...for example it was great that the OT and physio came to visit on same day"*

Martine (33 years) told us that her social worker co-ordinates everything

Darren (35 years) told us that his wife's care and support had been *"all joined up"* and he did not have to co-ordinate things, which he appreciated as he works full time.

Deirdre (64 years) told us that her Age UK workers had been very helpful generally in organising things and told her that she could ask her anything which was very helpful.

Debbie (64 years) said *"...services don't seem to share information. I know everything but the GP only knows his part, the social worker only knows her part and I have to co-ordinate things..."*

Fred (82 years) said *"It's all organised and paid for privately (carers, respite, aids) and so we have to coordinate everything. The district nurse comes but we don't know what for and she does not talk to us..."*

Bob (63 years) told us that he has had to coordinate everything. He said *"...the health side has been a nightmare trying to find your way through. There should be more cohesion and working as one. It feels like a jigsaw puzzle but at the moment all the pieces are on the floor and, as a carer, you have to pick them all up and put them together yourself..."* He added that he can't believe that he has to keep telling the same thing to all the different organisations involved and that they don't share information.

Mandy (55 years), whose Mum has dementia said *"...the services do not work well together. I co-ordinate all her care. I feel like I am fighting all the time. I need more practical support for mum now as her needs have increased. We have had four different Social Workers and it's difficult as I always feel I have to start again with each one, I am always repeating myself."*

Sandra (47 years) said *"..one of the most difficult and frustrating things about being a carer is that the services are just not joined up and you keep having to repeat the information over and over again..."*

She told us that when her Dad was sent home from hospital with a catheter no one told them what they were supposed to do. As her Dad was confused he kept pulling it out. He was unable to empty the bag, but no service was available to do this during the day when his son and daughter were at work. Sandra contacted the district nurses to ask them if they could do this, but they said it was not their job. She was left trying to phone lots of different services to try to find who could help with this. She said *"... Amazon can keep a shopping history and yet people from health and social care just keep asking you to repeat the same story time and time again....."*

Just over a quarter said that there was very little co-ordination of services and that having to co-ordinate services and constantly repeat information was one of the most time consuming and frustrating aspects of being a carer. Service users did not always see this extra work and their care did not necessarily suffer as a result, but it clearly had a very negative impact on the lives of carers who experienced this. On the other hand, for those whose care and services were well co-ordinated by the Connecting Care team, this impacted positively on both the service user and the carer.

How are the services and support that carers have received helping them to care for longer?

Carers' lives were made easier when services were well co-ordinated and the person they were caring for was well supported. As several carers said "*..what helps him, helps me..*"

Sometimes quite small interventions had made a big difference to carers. One lady told us "*...Carers Wakefield got a stool that my Mum could sit on in the shower and that made all the difference to us...*" A number of carers told us that aids and adaptations had been made quickly available to them and that this had really helped them.

For others it was services such as daily visits from paid carers which were enabling them to cope for longer by taking over some of the burden of domestic and personal care.

A couple of carers mentioned the Community Matron as having really helped them.

A few carers had access to regular respite care, which they said really helped them, although only if the quality of that care was good. Carers reported very variable experience of residential respite care, which they had used, from what they considered the truly excellent to the truly appalling. Sending a loved one to a residential placement for respite which was of poor quality (in their experience) had in some cases caused additional stress to the carer and produced the opposite outcome to that which was required. They vowed never to use such provision again.

A growing number of carers seem to be aware of and making use of the MyTime money which enables them to go away, if they would like this. Those who had accessed this were very grateful.

Another service (not within the Connecting Care team but which staff often signposted to) was Care Link (a paid for response system) which many carers said had made a real difference to them in being able to continue caring. They told us it gave them peace of mind knowing they could call them, and that it was helpful if someone fell but did not need to go to the hospital.

The Connecting Care services which were most frequently mentioned by carers as helping and supporting them were Age UK and Carers Wakefield. The fact that Carers Wakefield could develop an ongoing relationship with carers was something which carers who had experienced this, particularly valued and found helpful.

In addition, one carer said that he found it helpful and reassuring to know what services are available "*down the line..*" as his wife had a terminal illness which would only get worse. He had been told what help would be available then and how to access it.

What carers told us about services that help them to care for longer

Alan (71 years) said *"...the OT came and got us a stair lift and some equipment which has really helped us..."*

Joan (78 years) has a bad back and difficulty standing long enough to cook told us that the daily "home help" carers who get husband up and dressed have been a great help to her.

Sheila (84 years) who had a bad hip and was finding it difficult to pick her husband up off the floor when he fell said that being able to call Care link *"..makes all the difference.."*

Brenda (82 years) told us that her Carers Wakefield worker has been *"really great"* and found her a befriender. She had also been able to support them to get help with getting incontinence pants/pads as her husband was doubly incontinent. They had been buying all of his pads themselves and having frequent "accidents".

Jean (78 years) told us that after her husband had a stroke some years ago they received no aftercare or help. However in the last year or so this has changed and *"..the help has been abundant and it's wonderful..."* She has a worker from Carers Wakefield, who visits every other month and she considers to be a friend and gets information about lots of services. She also said *"... I got £100 MyTime money to help us go on holiday and we would not have been able to do this without this money so it was very helpful..."*

Lionel (66 years) said that all the services they currently receive are good and that *"..I am well aware of the support that we can access and may well do so later down the line but for now we are where they feel they need to be..."*

Bob (63 years) said *"..The community matron was brilliant and got lots of things sorted.."*

Bert (65 years) told us that his wife used to have a really good community matron who has now left, but now worked in their local practice and so they could still access help from her.

Anne (60 years) said *"..I could sit and talk to X from Carers Wakefield. I don't think I could have got through this without her. I have been very lucky. I had lots of support and lots of information eg about Alzheimer's Café and I knew what was around..."*

Bill (65 years) told us of two quite different experiences following his wife (Vera)'s discharge in recent months. The first hospital (outside Wakefield) discharged Vera after two days with no after care and only a walking stick. She could hardly walk and her husband literally had to carry her out of the hospital because they needed the bed for someone else. There was no after care, no walking aids or adaptations provided. Within a few days of being at home and struggling Vera fell and broke her ankle and had to be re-admitted to Pinderfields. After discharge from Pinderfields Bill said the aftercare was fantastic. They were seen by someone from Age UK who got them a wheelchair from the Red Cross plus a Zimmer frame and commode. He felt that if his wife had had all this after discharge from the first hospital then she would not have slipped and broken her ankle.

Arlene (60 years) said *"...we have a monthly meeting with the Carers Wakefield. Our only help is from them..... but we need so much more..."*

What has been unhelpful from the carer's perspective?

Carers told us of some very poor experiences of health and social care, which were unrelated to Connecting Care. Where these were raised, Healthwatch recorded these and will feed them back separately (and still anonymously) to the organisations concerned. In all cases interviewees were told that this is what would happen.

These included:

- poor care in hospital and poor communication between hospital and GP
- difficulties in accessing or receiving care from the Macmillan service
- difficulties with care received from the community nursing service
- poor care received from private care companies
- poor residential respite care
- poor support after someone had died including from funeral companies.

In most cases, the poor support that we were told about was the flip side of the good support described above. For example staff promising to get back to them, but never hearing from them again, poorly coordinated care, lack of services, lack of information etc.

Whilst paid carers provided a great deal of support to many carers, dealing with paid carers and care companies could also be a source of stress. In some cases carers had had to change carers' company several times before they found one that was reliable. We heard a number of very concerning stories about paid carers. We were told about paid carers who:

- were inexperienced (for example - one paid carer sent to look after a disabled lady with very complex needs had less than 2 weeks experience)
- did not turn up for visits so that people missed meals or toileting
- were rushed and did not have time to carry out required tasks
- did not stay for the allocated time
- did not understand how to speak with or look after someone with dementia
- left doors unlocked
- took no notice of the care plan e.g. turned up one at a time to use a hoist which required two people
- spoke to the person being looked after in a very patronising way
- were dismissive when carers tried to raise concerns with them
- left a mess behind which the unpaid carer had to tidy up – dirty washing, dirty and untidy bathroom, dirty crockery etc
- stole food and goods from vulnerable service users (two carers told us of incidents of stolen jewellery and money which they had reported to the police)
- were pressurised to work when ill, therefore spreading infections to vulnerable service users.

Many carers that we spoke to told us that they had never heard of Carers Wakefield, but were very interested to find out more. Other carers were aware of Carers Wakefield, having been told about it, or been given a leaflet by Connecting Care staff, but had an incorrect understanding of what services it offered. For example they thought it only offered support groups, but were unaware of the 'one to one' support that it could offer. In these instances the interviewer from Healthwatch agreed to provide further information to them or make a referral (again with their consent).

An example from a carer who was struggling to get help, and how Connecting Care helped her and her family

Fiona is 48 years old and lives in Scotland. Her Mum Moira lives in Wakefield and is supported by her son, Fiona's brother, who lives locally and visits her every day. This interview was conducted by telephone, but Fiona feels it is important that her story is heard.

Mum was admitted to hospital in the autumn of 2015. After her discharge home it became apparent, very quickly, that she needed to be assessed, as she was forgetting to eat, leaving the gas on at home and becoming very confused. Fiona and her brother tried to get their Mum assessed by Social Care and described this process as a nightmare and a battle.

They also approached Moira's GP but said they were "*fobbed off*." and told this was because they (her children) were not registered as patients. The GP was slow to respond and she had to battle with the practice when she felt it was very clear to a lay man that Moira had dementia. Fiona was becoming more and more concerned about her Mum's safety and getting extremely frustrated and angry because Social Care would not assess her Mum. As she describes it "*..I went into battle and sent three letters of complaint to Social Care and a letter to the MP. I made more than 12 phone calls and sent e mails...*" She told us that the whole experience was stressful and exhausting. She felt completely desperate and scared for her Mum and the family. It felt like no one would help.

She eventually heard about Carers Wakefield and went into their office and found them very helpful and supportive. Carers Wakefield involved Age UK who were also really good. They took time to listen and understand the issues and then started to organise help and support.

Age UK pulled the whole process together and provide information, advice and guidance around Moira's condition. Fiona and her brother attended a four week course in Wakefield delivered by Age UK which covered how to live with people with Alzheimer's, finances and the carers role. This course, she said, was very well run and they both found it beneficial.

Eventually, with the help of Age UK and Carers Wakefield, Social Care conducted a two hour home visit and Moira was diagnosed with Alzheimer's just a few months ago and she will now get the services and support she needs. In the event that Fiona needed to ask questions about her Mum's condition, treatment or support either in or outside of working hours she said she would contact either Age UK or Carers Wakefield.

They now have information regarding activities that their Mum can become involved in i.e. cafes and both she and her brother fully understand the services offered by Carers Wakefield and may access more of these in the future.

Fiona felt so strongly about the fantastic service of Carers Wakefield she visited her Mum's GP practice and told them to display Carers Wakefield leaflets because there are people like them that need to be able to access these services. She has since been into the surgery to check they are on display and is pleased to report they are displayed prominently.

What other services would have been/would be helpful for carers?

We asked all the carers what other services would have been/would be helpful to them. Whilst many were unable to think of any services which they felt would have been helpful to them a number were able to come up with some helpful suggestions which are listed below. We have used the exact words of the carers where possible.

- 1) More **practical support for carers** such as help with shopping or cleaning or moving furniture
- 2) **Support for young carers** – e.g. Glenn (35 years) would like more support for his young daughter as she is doing quite a lot of the caring for her Mum and would benefit from some support
- 3) Someone to **ring carers occasionally** to check they are OK
- 4) Better **procedures for sharing information** so that carers could access information when they needed it and didn't need to keep repeating themselves
- 5) **Ensure carers are always involved** in decision making
- 6) A **support network** for the family of people living with a relative with **severe mental illness** to help you to understand and to cope.
- 7) **Regular home visits** from GPs or other services when someone is seriously and chronically ill. *"...they should not wait for you to send for them..."*
- 8) **Someone to talk to** would be really great. Someone who could listen to carers even if they could not do anything to help.
- 9) Health service staff should **explain things clearly** so carers can understand what was happening or might happen in the future ". Bill (65 years) said *"..it would be good if people could explain what will happen (to my wife) to me and what to expect. I don't understand what is happening or why, with her care.."* His wife has degeneration of the spine but he doesn't understand what that means or what the consequences might be. She only had one physiotherapy session at home and he doesn't know why. Another carer said *"..it's not knowing things that makes it really difficult..."*
- 10) **Support from social care even if you are self-funding**. Sandra (47 years) had tried to get help from social services, but as her Dad was self-funding was told that no help was available. As she pointed out, at some point her Dad will run out of money and *"the service will have to deal with him then"* and she felt that support from social care before that point (e.g. giving information and signposting and getting to know her Dad) would be really useful.
- 11) There should be a **widely publicised single point of contact** for Connecting Care services. Patrick (53 years) said *"...some sort of one call number that you could phone for advice would have been really good. Someone who could give you advice and sign post you. I got the number for SPOC but they just kept telling me that Mum was not on the system (because she had not been given a social worker) and they couldn't help me..."*
- 12) It would have been good to have a **back-up plan**. One carer said he was doing everything and coordinating everything, He had no other family or other support. If he had become ill then what would have happened?
- 13) It would have been good to have **information regarding what aids and equipment they health or social care will provide** and what we could buy ourselves especially where it was quicker to buy it.

4. DISCUSSION AND IMPLICATIONS OF FINDINGS

It a rare opportunity, and a privilege, to be able to meet so many carers, face to face, have time to get to know them and to find out about the reality of their lives and experiences of caring. The majority, of carers that we met, would not have been able to participate in this project if we had not been able to go and meet with them where they lived. Many were only able to get out for short periods of time due to their caring responsibilities or other restrictions, such as their own poor health.

We have tried, as far as possible, to keep the focus on the needs of the carer. However, in reality it is often difficult to separate the needs of the carer from the person that they are caring for. And so our focus is also on the services received by the service user/patient as these have a substantial impact on the carer too.

Having detailed the findings from our interviews we now discuss, in this final section, what the implications of these findings might be, both for current service delivery and future service developments.

Some overall comments

Based on our overall analysis of the interviews completed, once we had completed them, we estimate that around a quarter of carers had experienced really excellent care and support from Connecting Care, whilst a quarter had experienced very poor care or support (usually because it was very limited). The others that we met had experienced a mixed picture.

This was a qualitative piece of work; we have not undertaken any statistical review of our findings. The purpose was to really listen to carers' experiences and views and understand from this how Connecting Care had impacted on their lives. Our impression, from the interviews, was that there was not any area of Wakefield where support for carers was better or worse than any other.

The carers who had experienced the best levels of support were not concentrated in one particular area. Carers who had experienced the most problems appeared to be more concentrated in the group which did not live with the person that they cared for. It is not difficult to understand why this may be so - it is clearly easier for Connecting Care (and other) professionals to communicate with someone who is there when they visit or phone. This group of carers (who did not live with the person they cared for), were also generally younger and were caring for parents or friends/neighbours.

In some cases they appeared to be unknown to services which were supporting the patient/service user. This meant that they were less likely to be involved in decisions about the care of the patient/service user and their opinion and views, which could have usefully informed better decision making about care planning, were often not taken into account. Only one carer who did not live with the person they cared for (Fiona in the case study on page 25) had had support from Carers Wakefield and that was only because she had found out about this herself.

Communicating with carers, both to give and receive information, is clearly vital both to ensure the best possible service for the patient/service user and for the carer themselves. It would appear that sometimes services need to give more thought as to the best way to include and communicate with carers, particularly when they do not live with the person they are caring for.

Accessing help

As detailed in the findings section, the carers that we met and interviewed:

- were predominantly elderly themselves, or caring for someone elderly
- often had their own significant health needs
- often had additional support from other family members, without which, they said, they would struggle to cope
- often felt lonely and isolated
- were mostly caring for someone whose health was declining, and
- were occasionally unknown to supporting services.

In almost all cases, without the support and input of the carer, the patient/service user would be unable to cope and would most likely end up needing to be cared for in some kind of residential provision, be it care home, nursing home or hospital. Supporting carers is not just “the right thing to do”, but is clearly an area where focusing effort and resources has the potential to deliver substantial savings in both the personal cost to carers’ health and wellbeing as well as to the public purse.

If carers are to be supported to care for longer it is paramount that the considerable impact of caring, on their own mental and physical health, is prevented or minimised as far as possible. Of course, each carer’s circumstance is unique and an assessment of each individual carer’s needs will be vital, but what was striking, during the interviews, was just what a significant impact caring had had, and was having, on so many carers’ mental health and wellbeing.

We met many carers who were well supported and even with first class support, carers told us that their roles could be extremely emotionally and physically draining. As mentioned, some carers received extensive help and support from members of their own family or (occasionally) friends. We also met many carers for whom Connecting Care had brought all the support they needed and helped to make a challenging and difficult role easier. These carers had been able to access the support that they, and the person they cared for, needed, when they needed it, and in a way which was able to meet both of their needs.

In some cases, however, despite the Connecting Care team approach, some carers (and service users) had experienced mixed or only minimal input and it felt as if an opportunity to bring in more services to support them (especially from Age UK and Carers Wakefield) had sometimes been missed.

Sometimes, carers appeared not to be known to Connecting Care services. If the service is not aware of the existence of a carer (which was more likely for the 21% of carers who did not live with the person they cared for) then it will clearly not be able to help them. It appears that some GPs and hospital staff are still not referring eligible people to the Connecting Care service and that members of the general public often just don’t know where to turn when someone needs an additional level of care and support in their own home.

Some carers had really struggled whilst on the Social Care waiting list. We know from talking with staff that it is possible to refer carers to Carers Wakefield (e.g. as part of the initial triage process) whilst they are waiting for a full Social Care assessment, but we are not aware how often this happens. It might be, given the financial constraints affecting Adult Social Care, that this approach needs to be taken more consistently and robustly to ensure that carers can access support from third sector services, whilst they are waiting.

For others, however, it was difficult to work out why carers themselves had not been offered some of the support that services such as Age UK and Carers Wakefield could offer.

In some cases carers had been offered services which they had refused (for a variety of reasons) or been given information which they had not retained or had misunderstood. Many staff told us during the staff interviews (which are reported elsewhere) that they always leave a leaflet for carers about support services available and yet many carers that we spoke to expressed no knowledge of these services.

Given the following factors:

- the mental and emotional stress which many carers are under
- the fact that many are elderly themselves, and
- with well documented poor literacy levels across Wakefield,

it may be that an approach based on leaving a leaflet and telling people once about these services is not the most effective one. A more robust approach may be needed to ensure that carers understand and retain information about other support available to them and can therefore access it, should they need to, either then or in the future.

Some carers had come to Connecting Care via a hospital discharge (or had been discharged from hospital without being referred to Connecting Care and had to find another way into the service) and again, we know from discussions with Connecting Care staff that there is scope to increase the awareness of carers' needs from hospital staff. A minority of GPs also seem to be difficult for carers to access, as demonstrated by some of the stories that we heard.

Our findings suggest therefore that there is scope to improve access to services for carers through:

- raising awareness of the need for, and availability of, support for carers, amongst hospital staff so that more carers are referred sooner directly from hospital
- continuing to raise the need for and availability of support for carers amongst GPs and practice staff
- ensuring that carers who are waiting for a Social Care assessment are referred to Carers Wakefield at point of triage or whilst waiting
- Identifying an approach for raising awareness amongst carers of Connecting Care service users about the support services available to them in a way which they can retain.

Providing information as standard to carers

Many carers had been frustrated by a lack of information or access to information about how and where to get help and support. A number told us that they just didn't know where to go or even what questions to ask, when they first took on the carer's role and this had often been a huge source of stress for them and the person they were looking after. Some carers had some really good suggestions as to what information it would have been helpful for them to know at the beginning of their journey as a carer. A summary of what they suggested is listed below:

- information about aids and adaptations – where to get them (either privately or state funded)
- information about finding, managing and paying care companies

- information about how long you might have to wait for various services
- information about how to put consent processes in place so they can access and provide information to/from health and social care professionals
- information about how to get help for them as a carer
- information about respite care available – privately or state funded
- information about benefits and financial allowances for carers
- information about managing incontinence and where to get products from – either privately or state funded.
- **all** of this information in one place.

Ensuring carers know what to do if things get worse

Our understanding is that the Connecting Care service has been designed, for the most part, to offer intensive and rapid support and interventions, and to set things up so everyone is supported - the focus being on rehabilitation and crisis intervention. However, for many of the people we met (both carers and service users) the likely future is one of worsening health and decline. Elderly people will become older and frailer, and people with conditions such as dementia and terminal disease face a clear future of declining health. For some carers, looking after people such as these, there also seemed to be an absence of planning for the inevitable declining future of service users which left some them (the carer) struggling and frustrated.

Many carers were worried that they:

- did not know who to contact if they needed increased levels of help and support
- did not have a “crisis” plan or “plan B” or any kind of plan in place to deal with inevitable decline or if they as a carer, became ill and/or could no longer cope.

Given the age and health status of many of the carers, these were realistic and very legitimate concerns. Even where the carer was relatively young and fit, they were often holding everything together and it was clear that, without them, the service user would be unable to live safely in their own home without the involvement of the main carer.

For some it might have been that, at the time of their last contact with Connecting Care staff, carers were coping a lot better, but then later, due to the deterioration in (their own or) the health of the person they were caring for, that their needs for support had increased. We know, from Connecting Care staff, that on discharge from the service, people are given a contact number and advised to ring back if they need the service again, but

- elderly people in particular are often reluctant to pro-actively “bother” health and social care professionals
- information or contact details may be lost or forgotten
- carers are often unable to identify or prioritise which services to speak to and end up being “passed around” and end up frustrated
- some carers or service users may have originally been referred to Connecting Care for service A, but now require service B. Most carers had no idea that these services are based and work within the same team and so would not automatically come back to the team for advice and guidance.

The impact all of the above is likely to be that carers are more likely to struggle on until their own health is further damaged or to phone 999 for help and end up with their loved one as an inpatient. Unnecessary hospital admissions are one of the things that Connecting Care is seeking to reduce and therefore developing an approach for agreeing a plan with carers which is explicit about what to do if things deteriorate (for them or the service user) would seem to be a useful way forward.

In addition, making short and longer term plans and expectations clear to carers would be helpful as some struggled to understand why some services were not available to them or were only available for certain periods of time.

Offering ongoing support

Carers who received ongoing support from Carers Wakefield or another source, told us how helpful they had found this. In particular, they valued an ongoing, relationship with a worker who they felt really cared for them as an individual.

For some carers, their need for ongoing support might be something as simple as a phone call.

As one carer put it “.. it would be good if someone could just phone you every now and then..”

Other carers also said they would have found this helpful and reassuring. For those carers who receive one to one support from Carers Wakefield this is already provided. People with a close relationship with a Carers Wakefield or other staff member, consistently felt that they could go back to that person to ask for help (or for signposting or referral to help) if their needs, or the needs of the person they cared for, increased. We met (and referred on with their consent) some carers who did not currently get this level of support, but felt that they needed it.

It is possible, however, that there is another group of carers who would benefit from a lower level of support both to provide reassurance and to more pro-actively identify any deterioration in the health and wellbeing of carer or service user/patient before carers reach crisis point.

The impact of this would be that, rather than relying on carers to remember where, when and how to source the support when they need it (which also presupposes that they are clear about what criteria justify this - i.e. how desperate do they need to be?) that a lower level of input, involving a short phone call at agreed intervals, would be helpful to signpost and support those carers who do not need more intensive support.

There may be other and better solutions and it would be good to get the views of Connecting Care staff as to how this could best be managed to ensure that carers do not reach breaking point before trying to get more help.

Social isolation and loneliness

It is well documented, through national research and survey, that many carers suffer from social isolation and loneliness¹ and that this can impact significantly on their health and wellbeing. The Campaign to End Loneliness² reports that social isolation and loneliness have been proven to cause depression and have a negative impact on physical health equivalent to smoking 15 cigarettes a day.

¹ Carers UK (2014) *The State of Caring*

² Campaign to End Loneliness (2016) <http://www.campaigntoendloneliness.org/loneliness-research/>

Our findings definitely support this. It was clear from our interviews that many carers in Wakefield were socially isolated and felt quite lonely. We know from the user survey results that this is also a problem (apparently increasingly so) for patients and service users.

It would appear that there is a need for Connecting Care staff to address this problem more consistently for the carers who support their patients and service users. The first step in doing this would be to ensure that there is better identification and assessment of social isolation (for carers) – maybe as part of the initial (and ongoing) assessment of all patient/service users by any of the Connecting Care services. Doing this would require:

- identifying and getting contact details for all unpaid carers
- getting consent to contact them
- assessing and identifying whether loneliness or social isolation is a problem for them

Staff could then signpost or refer carers to services, such as befriending services, community groups etc that could help them, in a way that works for them (as individual needs are likely to differ). It may be that, whilst the befriending services offered by Age UK and Carers Wakefield are useful for some, that other solutions are needed for carers who want to go out to socialise such as:

- arranging good quality respite or replacement care whilst they are out
- arranging transport for them
- finding suitable places where they can go to socialise and meet others.

As this appears to be an area of increasing need, it may be, in addition to local solutions within the Connecting Care team, that a more strategic, cross Borough approach to this problem is needed and that this needs to become more of a priority across the public sector.

Shared patient records

The lack of one shared patient/service user record is likely to make some of the above difficult (e.g. sharing information about social isolation and carers' other needs), but it needs to be an aspiration for the Connecting Care services that they should capture and share basic information about all carers (of people using their services). This should include, as a minimum: name, relationship, contact details, consent to share information with them - and should specifically include speaking to them either face to face or by phone. This would also be an opportunity to capture information about:

- carers' own physical, mental and emotional health
- carers' views on the health and social care needs of the service user
- whether carers feel they are lonely or feel socially isolated
- whether carers needed to be referred for a full carer's assessment.

This would then enable staff to ensure that all required information has been accurately captured and that all carers can be properly supported and signposted or referred to other services as required. This process should also ensure that carers have systems set up so that they can access information held by healthcare professionals such as GPs, as we know that this had caused problems for a number of the carers that we spoke to.

Some carers complained that they had to keep telling the same story and sharing the same information over and over again with different health and social care professionals. Having one shared patient/service user record (or shared, easy access to all records) would also help carers in reducing the number of times they have to tell their story to different people. Having said that, in some cases the people they were telling their story to over and over again were from the same service (e.g. the lady who said they had had four different social workers and so had to keep telling their story again) or from a service external to Connecting Care, e.g. primary care. And so to be truly effective, the shared record would have to be accessible to (and used by) these services too.

Community Matrons

We know, from other local work, that during the period of these interviews, the community matron service has been substantially reduced and the role re-defined several times. It is not therefore surprising that so few carers mentioned having received help or support from this role. The two carers who did mention this service were effusive about the help that had been provided by them and it seemed that the role (as they experienced it) had been able to provide really useful help and support both to the service user and to them as carer. We would suggest, therefore, that considerations regarding the future of the community matron service need to take into account, not just its impact on vulnerable service users, but also on their carers.

What can we do about poor service from care companies?

It would be disingenuous not to discuss the implications of what carers told us of their experiences with paid carers. Although this service is not provided by Connecting Care staff they have often been involved in commissioning it and/or signposting to it. Whilst these services had been enormously supportive for many carers and patients/service users, they had also caused some significant problems due to the poor or erratic quality of the care provided. We met a number of carers who had had to change the care company that they used several times (one person had used four different companies) before finding one which was reliable. The same was true of residential respite care. The carers that we met had little experience of day centre care and so we are unable to comment on the quality of this service.

This is not an easy issue to address, but it is certainly the case that many carers could have benefitted from some support to help them deal with the issues that they had with these companies, as it was a source of great stress to them. One carer did tell us that Carers Wakefield had been able to help her write a letter of complaint and to change care companies, so it might be that, providing Carers Wakefield support to more carers could also help them with this issue.

The wider issue of the poor quality of care provided by some of these companies is one which Healthwatch will continue to monitor and pursue.

Young carers

There is national data (ONS, 2013a) showing an increase in the number of young carers across all areas of England and Wales since 2001. However, we only interviewed one young carer, as part of this project, although we met another young girl, who was caring for her disabled mother, when we interviewed her father. This means that we have limited experience of what their needs and views might be. It may be that more work is needed in Wakefield to capture and identify the needs of this group in order to ensure that there are appropriate services to identify and meet them.

Conclusions

There is no doubt that it is very difficult to separate the needs of the carer from the person that they are caring for. However well the carer is supported, if the person they care for does not or has not received the care and support that they need, then this is likely to impact negatively upon the carer themselves; both on their day to day lives and on their health and wellbeing.

The Connecting Care approach potentially offers an integrated local team approach which is able to offer this “holistic” support. During our interviews we heard some fantastic examples where both carer and the care recipient had experienced a high level of well co-ordinated support delivered to them in their own home. For these people, the service was clearly enabling them to safely and effectively support the service user in their own home (where they wanted to be) and to enable the carer to care for longer. The Connecting Care service and approach had most definitely been effective for these people.

The Connecting Care services which were most frequently mentioned by carers as helping and supporting them were Age UK and Carers Wakefield. It is clear that having these two services within the Connecting Care teams is enabling a greater and more comprehensive service to be offered to carers. The fact that Carers Wakefield could develop an ongoing relationship with carers was something which carers who had experienced this, particularly valued and found helpful.

We met other people where the picture was mixed. Maybe the services delivered to the service user/patient were good, but the carer felt isolated and unsupported personally. Or the carer had found it difficult to access services, which were good once accessed, but the process of trying to organise things had taken their toll. Around half of the carers we spoke to, fell into this middle group.

There was an additional group of people (around 25%) who had received very poor support and services. In some cases, this was around difficulties in accessing the services in the first instance – both finding out about and locating services and waiting (e.g. on a waiting list) for access. For other people it was really not clear why, despite very clear needs (both for service user and carer), they had not been offered the support which they obviously required. Several of these stories related to end of life care. The carer was not always clear why they had not been able to get the help that they needed.

There may be a useful further piece of work to be undertaken, carrying out some “deep dive” case reviews (subject to proper consent procedure) to establish where there were opportunities to offer support that had been missed and how this might be used to drive service improvements.

A final word to the carers that we interviewed:

We would like to end by saying thank you once again to all of the carers that we interviewed as part of this project. Thank you for taking part in this work and taking the time to talk to us honestly, in the hope that services can continue to be improved for other people like you. Thank you for all your work as carers. Health and social care services, and society as a whole (as well as the person that you care for) benefit immeasurably from the valuable role that you do.

5. RECOMMENDATIONS

Number	Recommendation
R1	<p><u>Capture and share information about carers</u> The service should consider how to better capture and share information about carers (with their consent) in order that they can</p> <ul style="list-style-type: none"> - ensure they have details for all carers - identify those who need more help and support - ensure that carers go on to access or be provided with this support <p>This should include special efforts to identify and offer support to those carers who do not live with the person they care for, and young carers.</p> <p>The work on bringing together patient/service user records and information across the Connecting Care teams should be asked to ensure that data on carers can also be shared across the team.</p>
R2	<p><u>Improve the provision of information about services and support for carers</u> Connecting Care team members and their managers need to consider how they can make information for carers much more easily and quickly available and accessible whenever they need this. This should include information on all those areas, identified by carers, as important to them (listed below)</p> <ul style="list-style-type: none"> ■ information about aids and adaptations – where to get them (either privately or state funded) ■ information about finding, managing and paying care companies ■ information about how long you might have to wait for various services ■ information about how to put consent processes in place so they can access and provide information to/from health and social care professionals ■ information about how to get help for them as a carer ■ information about respite care available – privately or state funded ■ information about benefits and financial allowances for carers ■ information about managing incontinence and where to get products from – either privately or state funded. ■ Information about the quality of paid-for care services (where available) to allow people to make informed choices ■ Information about what to do if they or the service user/patient requires more support ■ all of this information in one place.
R3	<p><u>Improve access to information for carers about the person they are caring for</u> The service needs to consider how services can more proactively share information with carers and recognise their value in sharing the care of the patient/service user.</p> <p>It should be made easier for carers to access information about the person they are caring for and equally for them to provide information to services which support that person. Again, extra efforts may be needed to communicate with those carers who do not live with the person they care for.</p>

	There is a need to consider whether flagging up consent to share information with the carer could be done routinely for all carers early on, so that systems and consents are in place, especially with GPs.
R4	<p><u>Improve access to support for carers when they first need it.</u> It was clear from the interviews that a substantial number of carers had struggled for some considerable time before being able to access help and support for themselves and the person they were caring for. Work needs to be done with GPs (and primary care in general) and hospital staff (particularly those staff who discharge patients) to ensure that they are aware of the services available to carers and listen to and support carers to get the support that they need following discharge (or in some cases this could be initiated before discharge.) For example, a carers' information pack, provided to carers during a hospital admission, could be a useful approach alongside good discharge planning.</p> <p>Consideration should also be given to publicising the services of Carers Wakefield and the Hubs more widely to the general public.</p>
R5	<u>Address poor service from care companies.</u> Healthwatch should collate and publish feedback from carers regarding poor service from care companies and push for improvement. Carers Wakefield, and other CC team members should support carers in addressing poor care.
R6	<p><u>Reduce social isolation and loneliness.</u> All Connecting Care team members should include ongoing assessment for social isolation and loneliness of carers during all contacts with them, ensure they are aware of the various services available to help with this and refer or sign post on carers to these services.</p> <p>There is a need to ensure that all staff are clear what services are available to address this, and that any information provided to carers is easily available, user friendly and accessible whenever they need it.</p>
R7	<u>Reduce social isolation and loneliness.</u> Consider whether the Council could do more to raise the profile of loneliness as an issue, and put in place a more strategic and wide ranging cross Borough plan to reduce this.
R8	<u>Consider creating a care navigator/co-ordinator role specifically for carers,</u> who would work with, or support the development of, other schemes in the district including social prescribing, counselling, telebuddying and proactive contacts to check how carers are coping
R9	<u>Improve support for carers of people with terminal illnesses.</u> Based on the interviews that we did with carers who had cared for someone who was dying, there is a need for far more proactive support to be offered to carers who are caring for loved ones who are dying. They should be supported to understand what is going to happen and what they should do, and offered help to cope with the practical and emotional strain.
R10	<u>Improve support for carers whilst awaiting a social care assessment.</u> A number of carers and service users had struggled whilst awaiting a social care assessment. The service needs to identify how they can be more consistently supported during this time, eg through signposting to services such as Age UK and Carers Wakefield.
R11	<u>Identify those patients and carers who would benefit from a crisis plan</u> and work with connecting care staff and carers to identify how this could most effectively work.
R12	<u>Understand why some carers did not get the support they needed.</u> It would be good

	to undertake “deep dive” review of those cases where support had clearly been lacking, to identify why this was not delivered. It might be useful to present/discuss some of these cases at Connecting Care team meetings such as network meetings so that lessons can be learned across the team, with regard to better supporting carers.
R10	<u>Ensure that when service changes or reductions are made that the impact on carers is taken into account, as well as the impact on service users and patients.</u> For example the role of community matron had clearly been helpful in supporting those carers who had access to it.
R10	<u>Co-produce improvements with carers and service users.</u> In order to ensure that improvements are focused on what carers really need (rather than what professionals think they need) it would be helpful to include carers and service users in co-production of relevant service improvements.
R11	<u>Capture views of Connecting Care staff on how improvements could work best.</u> Improvements need to work both for carers and for Connecting Care staff, as they have the best understanding of how services currently work and the realities of delivering such support.
R12	<u>Ensure that Carers Wakefield and Age UK services are funded to cope with the impact of the extra workload which should occur if a wider number of carers are identified and signposted/referred to support from them</u> (through implementing the above recommendations)

APPENDIX ONE
COPY OF THE CARERS SEMI-STRUCTURED
INTERVIEW PROFORMA USED

CARER INTERVIEWS
Connecting Care evaluation – semi- structured interview
proforma

Date of interview:

Name/initials of interviewers:

Please could you start by telling me a bit about yourself

Prompts: e.g. how long have you lived here, what did you do before you took on caring role. Any hobbies or other responsibilities, volunteering? The purpose is to get the person to start to talk and think about themselves.

What is a typical day like for you?

Prompt: Good day/ bad day

Please tell me about the support and care that you have (have had) to give to <name>

Prompt: e.g. washing and dressing, toileting, cleaning, help with medication, help with shopping, food preparation, washing and ironing clothes, taking the person out, co-ordinating services.

How long have you been giving this care for?

What other help (or services) does <name> have?

Could you tell me a bit more about <name> (the person that you care for)

Prompt: this could include anything not already raised such as any more information about their health or social circumstances which are relevant

If several different people or services are involved....what is your experience of how (well) the different services work together?

Prompt: Does the carer have to play a role in co-ordinating services? Does the same information have to be provided to different people?

As a carer, what help and support do you get?

Prompt: if not covered prompt financial support, access to respite breaks including My Time carer breaks. Any contact with carers support organisations or other voluntary sector?

Has this been helpful for you?

Prompt: explore how this helped or did not help if not covered

If you need to ask questions about your relative/friend's condition or treatment or support who would you contact/ask? a) in hours b) out of hours

Prompt: non-emergency

How is your health and how are you coping with all your work as a carer?

Prompt: if not mentioned, ask about social contact, mental and physical health

What (other) services or support do you think would be (or would have been) useful to help you as a carer?

Are there other things that could be (or could have been) improved to make your caring role easier?

Do you have any other comments (either good or bad) about the services which you or <name> have received which you think would help to improve them for other people?

CARER DETAILS

Sex: Male Female

The Carer is the service users: Friend Spouse Sibling

Child Other

Neighbour Partner

If "other" state here _____

Age of carer:

Do you live with the person you care for? Yes / No

Ethnic origin:

White

- 1 British
- 2 Irish
- 3 Any other White background

Mixed

- 4 White and Black Caribbean
- 5 White and Black African
- 6 White and Asian
- 7 Any other mixed background

Asian/Asian British

- 8 Indian
- 9 Pakistani
- 10 Bangladeshi
- 11 Any other Asian background

Black/Black British

- 12 Caribbean
- 13 African
- 14 Any other Black background

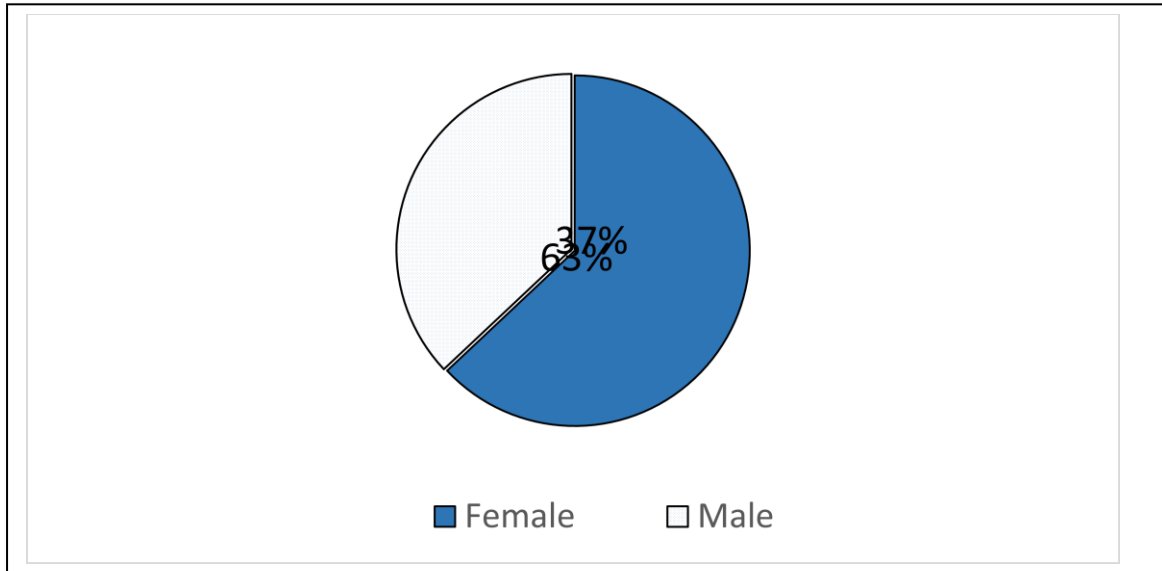
Chinese and other ethnic groups

- 15 Chinese
- 16 Any other ethnic background

Postcode: _____

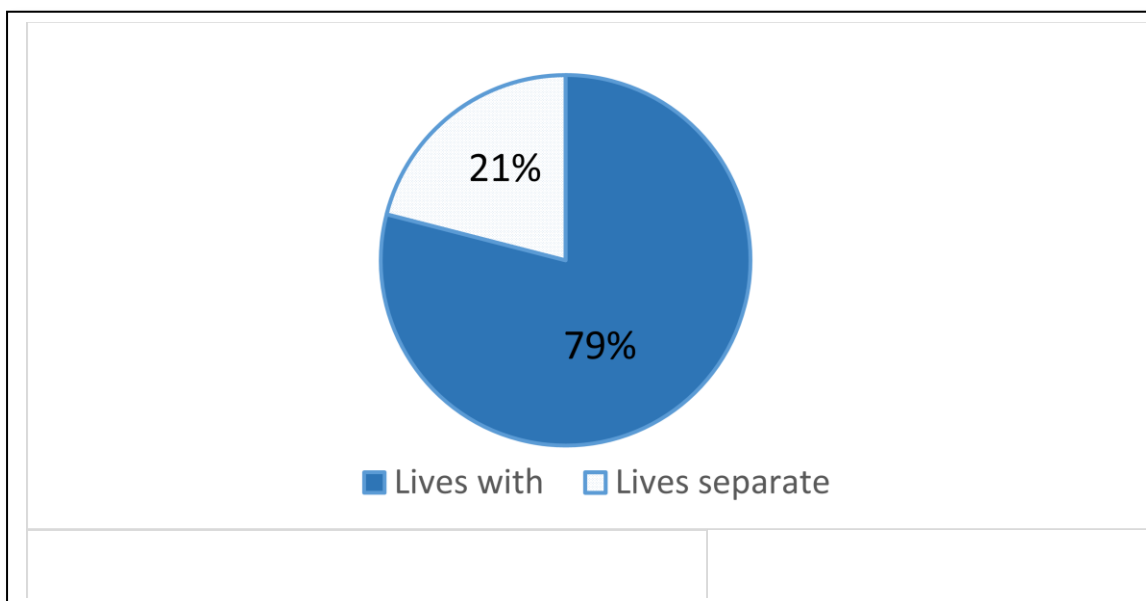
APPENDIX TWO
CHARTS SHOWING DETAILS OF CARERS
INTERVIEWED

Chart one – Carers interviewed by sex



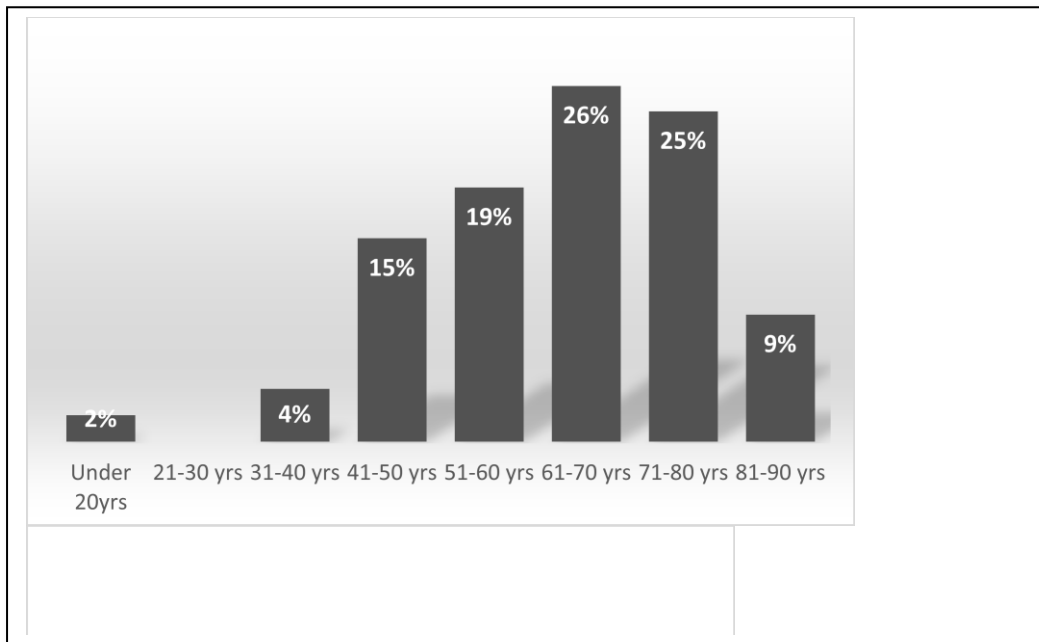
Just under two thirds of those interviewed were female

Chart two – Carers interviewed by place of residence



79% of carers lived with the person they cared for.

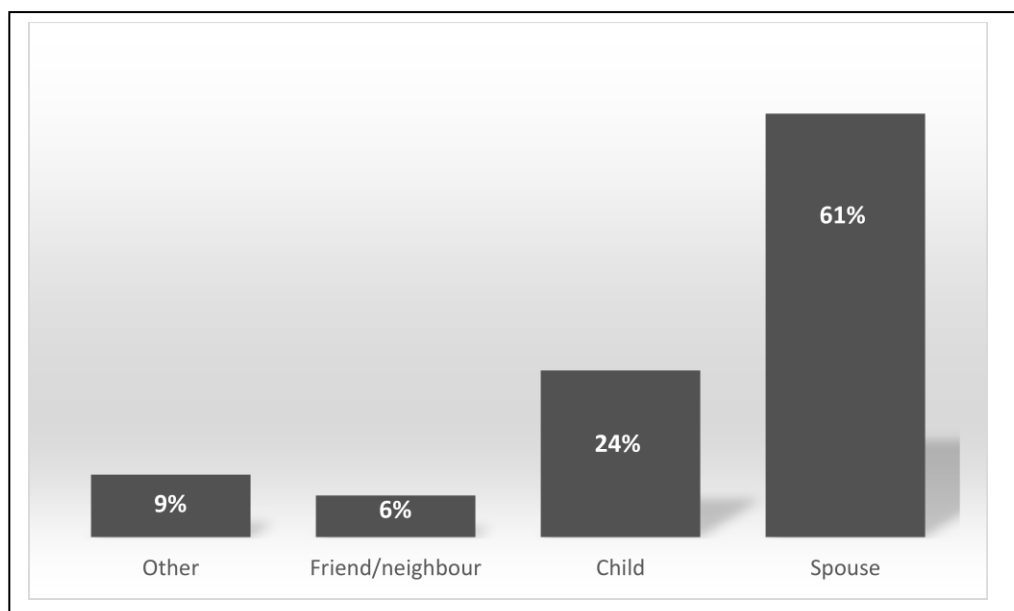
Chart three – Age range of carers interviewed



The majority (60%) of carers were 61 years or over, with 9% in their eighties.

The

Chart four – Carer's relationship to the person they were caring for



The majority of carers were spouses or children of the people they were caring for. The "other" category contained one grandparent, one grandchild, one mother, one ex cleaner and one sibling.

Chart five – post code of carers interviewed (Wakefield only)

