

# WEST NORTHAMPTONSHIRE COUNCIL CABINET

16 APRIL 2024

## CABINET MEMBER FOR ADULT CARE, WELLBEING AND HEALTH INTEGRATION – COUNCILLOR MATT GOLBY

Report Title	Carer Strategy
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### List of Approvers

Monitoring Officer	Catherine Whitehead	20/03/2024
Chief Finance Officer (S.151)	Martin Henry	20/03/2024
Other Director	Stuart Lackenby	20/03/2024
Head of Communications	Becky Hutson	20/03/2024

### List of Appendices

Appendix A – Draft Carer Strategy v0.9 (separate PDF)

Appendix B - Engagement Feedback (at the end of this document)

Appendix C – Patient Reported Outcome Measures (PROMs) (at the end of this document)

### 1. Purpose of Report

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- 1.1. To advise Cabinet of the engagement activity undertaken to understand the needs of our unpaid carers.
- 1.2. To seek approval for a 30-working day public consultation on the carer strategy before final publication.

## **2. Executive Summary**

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- 2.1 West Northamptonshire Council (WNC) and North Northamptonshire Council (NNC) have jointly commissioned carer support services from Northamptonshire Carers. The contract is led by NNC and both councils delegate Care Act (2014) statutory duties for carers, to this provider.
- 2.2 The contract is due to end at the end of September 2024 and NNC have requested a 6-month waiver. This is to allow time for both councils to develop a new service specification and will commission their own carer support services going forwards. Cabinet will be informed our intended commissioning approach during 2024.  
<https://www.local.gov.uk/sites/default/files/documents/Do%20I%20need%20to%20consult.pdf>
- 2.3 To support the respective strategic direction each council will undertake, both councils have developed their own carer strategy. The WNC strategy has been coproduced with West Northamptonshire carer experts by experience (EBEs). This report is seeking approval for public consultation on this draft carer strategy before final publication of the strategy. This is a very positive step for WNC and supports the assurance work for CQC inspections of local authorities.
- 2.4 A carers strategy will allow us to set out the direction of travel for the council over the next five years. The strategy sets priorities for the council with associated actions, written to tackle those issues identified in the engagement and self-assessment. It sets out the council's ambition to deliver the best services it can for the people of West Northamptonshire and fulfil its statutory duties for unpaid carers.

## **3. Recommendations**

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- 3.1 It is recommended that the Cabinet approve the 30-day carer strategy consultation.

## **4. Reason for Recommendations**

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- 4.1 Engagement sessions were carried out in all 9 LAPS before the strategy was written with WNC carers as part of a coproduction team. We held two online events and produced an online questionnaire.
- 4.2 Commissioners carried out a locally designed Care Act self-assessment. The results of the self-assessment and engagement feedback were used by the coproduction team to write the priorities and actions for this strategy.
- 4.3 The next and final step is to take the strategy for 30 days to public consultation. Feedback from consultation will be considered before the issuing of the final strategy.

## **5. Report Background**

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- 5.1 Carer numbers:
- The 2021 Census showed 31,723 people identifying themselves as carers in West Northamptonshire (based on averages of all the custom carer dataset queries).
  - The percentage of the population in a caring role in West Northamptonshire = 7.5%
  - The potential 2024 carer population of West Northamptonshire = 33,007

- Number of carers on the Northamptonshire Carers list - 10,984 (adults and child carers, December 2023)
- Shortfall in known carers (January 2024) = approximately 22,000

5.2 Headlines from the national carer survey 2024 (West Northamptonshire):

- Carers who accessed services were generally happy with them
- Only 1 in 5 carers said they had as much control as they needed
- 7 out of 10 carers said that the information/advice they received was helpful
- Overall carers reported feeling tired, depressed, and stressed

5.3 Carer finance:

With the current cost of living crisis, carers are facing unprecedented pressure on their finances (Carers UK data).

- A quarter of carers are cutting back on essentials like food or heating.
- 63% are extremely worried about managing their monthly costs.
- 44% of working-age adults who are caring for 35 hours or more a week are in poverty.
- Carer's Allowance is the main carer's benefit and is £76.75 per week (2023/24) for a minimum of 35 hours. It is the lowest benefit of its kind. In the UK, 977,506 carers were in receipt of Carer's Allowance in 2022.

5.4 Work and caring in West Northamptonshire:

- 36% of carers also work full-time.
- 19% of carers also work part-time.

5.5 Disability and caring in West Northamptonshire:

- 18% of carers are disabled under the Equality Act and their day-to-day activities are limited a little
- 10% of carers are not disabled under the Equality Act: but has a long-term physical or mental health condition but their day-to-day activities are not limited.
- 8% of carers are disabled under the Equality Act and their day-to-day activities are limited a lot.

5.6 The carer strategy supports the aim of the council's anti-poverty strategy for a fairer and more inclusive West Northamptonshire, where everyone can live their best life, prosperous and fulfilling, free from poverty and inequality.

5.7 The strategy aims to support people who wish to work but who also have a carer role by providing support, information, signposting, and a support plan personalised to the needs of the carer.

5.8 Carers can access advice on benefits such as Carer's Allowance, Attendance Allowance for the cared for person and advice on council tax exemption for severe mental impairment for example, so the carer effectively has a 25% discount on their council tax bill.

5.9 Two priorities support this: the development of a guide for carers in West Northamptonshire and a one-stop shop that will visit the respective LAPS as a peripatetic support service. This will be a source of expert advice.

- 5.10 Supporting the carer reduces carer burden and improves quality of life, reducing the risk of carer crisis. Carers are encouraged to plan for a potential crisis and appropriate support can significantly reduce this risk. Carer crisis can lead to hospital and care home admissions.
- 5.11 Our EBEs wanted an outcomes framework to prove the strategy will have an effect on carer burden and quality of life, as well as those measures commissioners may usually record, such as an increased number of carers being supported. Evidence based tools were explored and the following selected:
- Carer burden: Zarit Burden Interview
  - Care Quality of life: Adult Carer Quality of Life Questionnaire (AC-QoL)
- A baseline score will be recorded at the beginning of an intervention and then after a period of time has lapsed, depending on the circumstances.
- 5.12 The Care Act (2014) and Children and Families Act (2014) set out statutory responsibilities for carers. Our EBEs wanted people to understand their rights and so the main duties are listed in the carer strategy. These duties include a right to a carer assessment, a support plan, review of that support plan and information and advice. They set out how the market should be developed to support people and how carers should be safeguarded and provided with advocacy when they need it.
- 5.13 The Health and Care Act 2022 gave CQC new powers that allow them to provide a meaningful and independent assessment of care at a local authority and integrated care system level. They enable CQC to start to understand the quality of care in a local area or system and provide independent assurance to the public of the quality of care in their area.
- 5.14 CQC has set out a framework for inspection and that includes reviewing strategies a local authority produces to understand if these strategies support the local authority in fulfilling its duties under the Care Act (2014). Northamptonshire Carers were leading a countywide approach to developing a carer strategy but the statutory duty for carers lies with the local authority. Both NNC and WNC took the decision to develop their own carer strategy. Northamptonshire Carers have supported this by providing information to each council on the work they had carried out up until that point in time.

## **6. Issues and Choices**

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- 6.1 The strategy will be a framework for developing support for carers. Not just as a one-off but as a progressive process of positive change over the next 5 years. It recognises the increasingly important role that carers play in West Northamptonshire, alongside the wide variety of caring roles and the diversity of those within these roles and it acknowledges that carers need more help and support than has been available in the past.
- 6.2 The Care Act (2014) and Children and Families Act (2014) set out what support local authorities must provide for carers, as well as the cared for person. West Northamptonshire Council delegated these responsibilities when it commissioned with NNC Northamptonshire Carers to deliver these services for its residents. The current contract led by NNC is due to end at the end of September 2024. A 6-month waiver will be requested to allow time for the strategy to be published and separate models for NNC and WNC to be developed. The priorities set out in the

strategy will guide the development of a new carer support service specification, specifically aimed to meet the needs of the carers in West Northamptonshire.

- 6.3 The strategy has been developed with current carers of people in West Northamptonshire. People with lived experience of caring, referred to as experts by experience (EBEs) were recruited during the engagement events for this strategy and formed a coproduction group with officers of WNC.
- 6.4 Engagement events were held in all nine Local Area Partnership (LAP) areas with a mixture of morning, afternoon, and evening sessions. Commissioners held two online engagement events and comms' colleagues developed an online questionnaire. The feedback was used by the coproduction group.
- 6.5 The Senior Leadership Team requested commissioners assess WNC adherence to our statutory duties to carers under the Care Act (2014). Commissioners contacted ADASS and the LGA to ask if an assessment tool had been developed for this purpose. When commissioners were advised that they were not aware of a tool, one was developed in WNC. The tool was highlighted as good practice by the LGA and is now used by numerous other local authorities.
- 6.6 The results of the self-assessment led to recommendations resulting in WNC task and finish groups. These are to explore the interface between assessments of the cared for person and assessment of the carer and the direct payment model for carers. The results of the engagement events and self-assessment were shared with the EBEs, and they used this and their own experiences to develop the strategy.
- 6.7 There is no current national carer strategy to consider, and national carer voluntary groups have been campaigning for the government to put one in place. The last national carer strategy was, *'Carers at the heart of 21st-century families; (2008-2018)* and the Carers Action Plan 2018 – 2020.
- 6.8 The NHS Long Term Plan published in 2019 set out some priorities for carers and the main themes are detailed in the carer strategy.
- 6.9 The National Institute for Health and Care Excellence (NICE) carer guidance published in 2020 is included in the strategy. Nice carer guidance covers support for adults (aged 18 and over) who provide unpaid care for anyone aged 16 or over with health or social care needs. It aims to improve the lives of carers by helping health and social care practitioners identify people who are caring for someone and give them the right information and support. It covers carers' assessments, practical, emotional, and social support and training, and support for carers providing end of life care.
- 6.10 Although the EBEs were not aware of the NHS Long Term Plan or NICE guidance, the local priorities align very well with these national themes.

## **7. Implications (including financial implications)**

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### **7.1 Resources and Financial**

7.1.1 There are no new resources or financial implications arising from the strategy.

7.1.2 The strategy is a strategic direction for improved information, support and signposting for carers. It will include upstream interventions aimed at prevention. The new service specification for carers will take the priorities into account and be developed within the current financial envelope for the carer support model, currently being provided by Northamptonshire Carers. EBEs will be involved in the process from the start.

7.1.3 Northamptonshire Integrated Care System (ICS), led by WNC officers, submitted an expression of interest for the DHSC Accelerated Reform Fund (ARF). The expression of interest was a grant for three projects from a list of 12 national priorities. Five of these were for carers. The ICS chose two projects for carers (and another for shared lives) and these are areas identified for improvement in the self-assessment. Furthermore, they are priorities in the carer strategy. The projects are:

- Supporting carers to identify themselves as carers
- Identifying more carers for support.

This is a statutory duty under the Care Act (2014). Based on the 2021 national Census data, in 2024 there are approximately, 33,007 who identify themselves as a carer and many more that do not currently identify themselves as a carer. As of December 2023, Northamptonshire Carers had 10,984 people on their books – made up of adults and child carers. There is a significant shortfall of people yet to be offered support.

### **7.2 Legal**

7.2.1 The Care Act 2014 makes provision for the responsibility and statutory duty on a local authority to assess a carer's need for support, to include any possible future support, what those needs may be and how those identified needs will be met having been evaluated and if they meet the eligibility criteria. The strategy aims to improve the council's adherence to those statutory duties.

### **7.3 Risk**

7.3.1 By not having a carer strategy in place, the council risks criticism in the council's CQC inspection.

7.3.2 Not having a carer strategy increases the risk to the council of not meeting its statutory duties towards carers. The strategy aims to address areas identified for improvement and will address gaps in support and reduce the risk of carer crisis.

7.3.3 If carers are not adequately supported, the risk of carer crisis increases. Care crisis leads to the cared for person being admitted to long term care or hospital admission and has a negative effect on the carer's wellbeing.

#### 7.4 **Consultation and Communications**

7.4.1 Engagement events were held in all nine Local Area Partnership (LAP) areas with a mixture of morning, afternoon, and evening sessions. Commissioners held two online engagement events and comms' colleagues developed an online questionnaire.

7.4.2 To prompt engagement and input into the events / online questionnaire, a range of communication channels were used to share the messaging which include:

- Text and flyer included distributed to Town & Parish Councils
- Members briefing
- Community newsletter
- Community forums distribution lists
- Members of the WNC Consultation Register
- Members of the WNC Residents' Panel
- Regular social media messaging shared on all channels
- Cllr Golby Interview on NLive radio station
- Uploaded article to website
- Press release issued to all media outlets
- Issued via e-resident newsletters
- Article shared via Northants Carers newsletter and social media
- Internal mid-week update and news centre
- Shared via internal WNC Staff carers network
- Commissioners shared directly to providers / contacts / LAP leads

7.4.3 To support feedback and prompt responses to the public consultation, a comprehensive communications plan will accompany the public consultation launch using a variety of different channels.

#### 7.5 **Consideration by Overview and Scrutiny**

7.5.1 The strategy is not considered necessary for the Overview and Scrutiny Committee. However, there is a scrutiny sub-group currently taking place on carers and the group have requested to comment on this strategy during the consultation period.

#### 7.6 **Climate Impact**

7.6.1 No impact on climate.

#### 7.7 **Community Impact**

7.7.1 The carer strategy is aimed at significantly improving the carer support offer in communities. For example, one of the priorities is for a one-stop shop peripatetic service to move around the

LAPs. Some of the feedback from the engagement events was about what is perceived as a 'postcode lottery' for support where there is plenty in the towns and less so in the very rural villages. This strategy addresses those issues.

## 8. Background Papers

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### 8.1 The carer strategy v0.9 (separate PDF)

#### Appendix B Feedback from engagement

Age band	Good/Works well for carers
65-74	MK run an Art for Heath group which my husband attends. That is good.
55-64	Good support and understanding from Local authorities and other associated bodies.
55-64	Adult social services easily accessible 24/ 7
95+	The service to supply home equipment was very responsive and delivered items needed quickly when mum came home from a care home.
18-24	Northants Carers Groups
18-24	Carers Assessments.
85-94	Generally, I think the support for Carers is fantastic around the county as the range of information support and services.
35-44	Group sessions on a regular basis for the person I care for
45-54	I have seen nothing other than the help given to my children.
55-64	specific organizations which advocate and support me such as Dementia UK and Alzheimer's society
45-54	Support from Social Care, and support from Cransley Hospice
75-84	Support from other agencies and people
25-34	I feel that having the flexibility of a direct payment to arrange the day-to-day activities for my son helps with being able to arrange times when I can have time to rest and restore from my caring role.
25-34	Being able to have a care package for my son enables me to work
Under 18	Local groups such as Spectrum, A.C.E., Sports 4 Fitness, Em-power, Northampton Down Syndrome and SENDs 4 Dad
18-24	Support from (CALM) Northants Carers
85-94	Adult social care do their best but there's not enough
Under 18	Networking with others
25-34	Council departments are very good at providing services which each department specialises in. Support is often provided when requested.
85-94	We get support and guidance from the Good Neighbours scheme. We have a WhatsApp group for each of the elderly people that I support. This is very helpful for dealing with emergencies and keeping everyone updated on the wellbeing of the person from whom we are caring. For each person that I support there are a small group of us, all 'organised' by good neighbours so that responsibility is shared.



75-84	I am appreciative that I work for WNC and there is a carers policy and I have been able to engage with my senior about flexible working. Also, I had a conversation with a member of your adult social care team who was brilliant. She showed empathy and set out information clearly. I was very impressed.
18-24	Had great experience with young carers in the past
Age band	Not Good/Does not work well for carers
65-74	My husband doesn't feel he needs care following his stroke so doesn't see me as helping him at all despite him really needing to be with someone 24/7 and him not attempting to do anything for himself. I tried getting him to go to some carer events, but he wouldn't go.
55-64	Being handed over to another case worker or duty case worker
55-64	Being left to find care home or care supplier because you have enough savings to fund this type of care
95+	Services are also disjointed- a one-stop service for carers to use to bring together all services would really help.
95+	records aren't passed from one to another and so it means that I need to go through everything every time to make sure mum is getting the best care
95+	It is not easy to find the right care at home and particularly time consuming and difficult to do when working
95+	My mum pays for her care and will likely never need state support beyond attendance allowance. So yes, she can pay, but she is disproportionately disadvantaged as a result as everything had to be arranged personally
18-24	Communication between Education / Medical / Social / Council regarding services for the cared for person.
18-24	Social Care funding
18-24	Not enough support for Carers physically who need extra help
18-24	No support financially when struggling with paying bills / buying food and necessary things like clothes
18-24	No respite if needed to go into hospital or unable to care for carer person.
85-94	As someone who works and does not live with the people I care for, many services such as sitting is not accessible to us.
35-44	I don't receive any benefit e.g. carers allowance because I am on a state pension. I have raised energy bills etc e.g. tv has to be on all night to soothe carer
45-54	Although support is growing it is not available for men with families particularly those working
45-54	sympathetic people but no real solution
55-64	Lack of transport
55-64	sitting services and befriending for my relations due to dementia
75-84	It is not acceptable to be forced to step in to provide care in the absence of adequate and appropriate care from social and health services

75-84	It can be very lonely and frightening being a carer as you can feel very out of your depth and without the support of other agencies it can be debilitating and risk the health of the carer.
25-34	It's Isolating, no one is in your position where you have someone dependant on you
25-34	No support, full time job, constantly let down by services that are supposed to provide but routinely don't, so you give up and go it alone.
25-34	No consideration of carers own health or other needs, left until breaking point and even when carers tell professionals they aren't managing there often isn't any practical plan put in place. Very low-level support like support lines and groups don't help at times like this. Working carers don't get any financial support like carers allowance even though they are still doing the care and saving thousands. Very little funding for carers association to offer decent support
85-94	Not having someone to sit with the cared for person.
85-94	Not having someone to talk to who understands the problems.
25-34	Virtually no information published about respite providers for young adults with learning disability. The information from the Northants Care Choices Directory filters down to 4 providers for LD/autism and shows 2 photos of older women so possibly not representative of the service user.
Under 18	The area I work has no support at all. Most of the support only available if you have a car and you drive.
	Nothing works well. I didn't know there was any support for carers out there nor that a payment (benefit) could be claimed for doing so. Caring has blighted my life, affected my career, damaged my relationship with friends and other family members as I can't always be there for them and can't always join in and go places due to caring responsibilities.
75-84	I've cared for over 20 years and only found help 3 years ago when I made a trip to the doctor about increased falls/frailty, and they finally referred me and the person I care for a home visit (think it was Occupational therapy). From that, I found out about the lifeline through the council (but didn't realise it was part of the council as it had a different name Olympus?). They did a home visit and put in a few rails, steps etc but were unable to suggest some fixes to issues i.e. being able to get into and out of the bath independently as the stock items that are available are not bespoke enough to everyone's needs and also, they require a ridiculous amount of strength for the disabled person to use.
75-84	The occupational team eventually referred me to Age UK to see what benefits I or the person I care for might be eligible for but the very, very lengthy form was left for me to complete. It was long and time consuming but eventually the person I care for was give attendance allowance.
Under 18	Very limited parent carer support services provided. It will be good if there could be a way in which the smaller local groups were supported to be able to expand and grow what they are currently providing.
18-24	No carer assessment or support for working carers No overnight respite No transport for day centre which is 8 miles away and is the closest one

	No health and wellbeing support for carers in rural areas
85-94	The hospitals people are sent to like Isebrooke for rehabilitation care are not on the same system as the Northampton social services. So, my Uncle for example has been sent to the other side of the county. He's lived in Kingsthorpe all his life, but is placed out in Higham Ferrers and has been stuck in a discharge to assess placement for 7 months
85-94	Social services and intermediary care teams and temporary care homes should all be in communication they double up, or in my uncle's case he fell through the gaps and had none. Even with us contacting people. There's no respite for elderly carers, no one stop shop that can ensure all is well with elderly carers and the one they're caring for
85-94	One department assuming the others know
25-34	Over the years I have discovered groups, newsletters, and information by accident despite trying to source such items via browsing the internet.
85-94	We are not able to speak to the medics/social services to organise support or to seek advice
85-94	There seems to be no way to upscale the support that a person receives - there don't seem to be any contacts that we can talk to arrange a meeting with the elderly person
18-24	I am a carer by default due to lack of services suitable to support a person with ADHD and autism. Services seem to be missing for this particular age group which results in family members having to prioritise the person they care for
18-24	Support offered is for my mental health, but I would not be depressed if the person I care for was provided with some consistency from social care provision or education setting
45-54	A life of loneliness, isolation, and exclusion. We are the forgotten about, taken for granted section of society. Our own physical and mental health comes second place.
Age band	What would you do to improve support for carers
65-74	Provide some respite
55-64	Regular support from organisations for the carer
95+	A one stop shop/online hub for everything care related
95+	Joined up services ideally (a big ask but done in stages)
95+	Equal 'support' for carers of those that pay for their care - at the moment we are disadvantaged as we have a lot more work to do to sort services out.
95+	Voluntary care services also providing support/networking for people who are carers but work. At the moment everything takes place in the daytime
18-24	More emotional support
18-24	More emergency care / respite services.
18-24	More understanding of the medical / social care needs of the individual cared for person.
18-24	More flexibility at work / school for the carer.

85-94	More services or an expansion of current services for working carers and those who do not live with the cared for person.
85-94	Services such as the Needs & Aspirations, they are all in East Northants and again not accessible to many across the county.
45-54	Individual support for carers that works for the person and the carer they look after.
45-54	Tailor the package makes it less about what you can't do but what you can, time at the gym for physical and mental preparation and fitness.
45-54	Membership passes that don't make you feel like the kid with free school meals but instead the time out the deserve and need.
55-64	More respite without guilt or high costs please, I shouldn't be on my knees
55-64	More day centres that enable carers to breathe in safety and peace of mind - Affinity is amazing
75-84	Funding public health programmes to ensure that people can maximise their health outcomes and put less strain on the NHS and social services
75-84	I would ensure that all carers know that they can also access support to keep themselves well whilst carrying out this essential work.
18-24	Have consistency across the county, have services that provide; that don't just signpost you and leave you to find out things yourself.
25-34	Have carer health and well-being checks because we often put our needs last but if we become, I'll what will you do
25-34	Carer vouchers to use as we see fit massage, paying for gas, food, or a lunch with a friend
25-34	More understanding of disabled carers who struggle to access groups or what's on offer
25-34	Better awareness and understanding from social workers or professionals in general
75-84	More thought needs to be put into this by providing easily obtained support for families to allow the person to remain at home
blank	The Fire and Rescue Service would like to offer support to carers around safety in the home.
75-84	Ensure that occasionally there was a carer to sit with the person who needs care to relieve the permeant carer
75-84	Ensure that there was someone for the carer to talk to about the person who they are caring for.
25-34	Could Northamptonshire Carers publish a newsletter? <i>(They do)</i>
Under 18	Kings Sutton has no direct connection to any town or nearby village, but everything is offered is in Northamptonshire, Brackley, Towcester etc.
Under 18	I feel many times we are discriminated because we rely on public transport.
75-84	Make it easier for carers to find out about what help is out there for them.
75-84	Make employers be more flexible with working patterns to enable carers to work around their caring responsibilities.

75-84	Make sign posting and referral networks easier in the first place and make them easier to access.
75-84	Many of those that need caring for are not internet or mobile savvy so need communicating via different methods.
Under 18	Support the smaller groups that are more targeted on the local residents. There is additional strain on families with a SEND child. There needs to be better support for mental health and family support.
18-24	Health and wellbeing support which is accessible to carers in rural areas
18-24	More support for carers who work
85-94	It would be really helpful to have someone maybe attached to social services who could meet with the elderly person and the carer to discuss ways forward
18-24	A local drop-in centre similar to a crisis café ( <i>mental health model</i> )
85-94	If the carers had a chance to choose assistance from people directly employed by the council, there wouldn't be a withdrawal of care packages as we are seeing.
85-94	When a carer is on duty locally, they will end up going to the same families building up a rapport. Care shouldn't be making a profit from people or local councils it should be a service first and foremost.
85-94	Having a mental health team to help people handle the stress of palliative care and the need for respite for family is important too.
85-94	Carers who are elderly themselves end up needing hospitals due to extreme fatigue and feeling like they are on call 24/7
85-94	Avoiding gaps in care assistance is therefore imperative for young disabled too anyone who needs it. It would save money and improve lives if the cost of paying lots of different private care in the community companies was cut out.
85-94	At the moment it's a mishmash of different levels of quality care. Northampton could lead the way to integrating all the aspects of care. Outsourcing has failed
85-94	A new set of council run care homes small but with modern layouts is needed urgently
85-94	someone attached to social services, perhaps, who can advise/counsel elderly people who have no relatives, in planning their future.
85-94	Someone, perhaps attached to the local medical centre, who could visit elderly person to organise medication, check-ups, immunisation, toenail cutting, eye testing etc
45-54	Financial support for carers needs a total overhaul. We need to be paid properly for what we do considering most give up their own careers and live in poverty to do the right thing by their loved one. ( <i>several of these</i> )

## **Appendix C Patient Reported Outcome Measures (PROMs)**

## CAREGIVER BURDEN SCALE

Zarit et al. (1980), *Gerontologist*, 20(6), 649-55

**Instructions:** Read each statement and rate it on a scale from 0 (never) to 4 (nearly always)

In general, how often do you feel:	Never	1	2	3	4	Nearly Always
There is not enough time for yourself	0	1	2	3	4	
Overtaxed with responsibilities	0	1	2	3	4	
Like you've lost control over your life	0	1	2	3	4	
<b>In regard to the relative for whom you are caring, how often do you feel:</b>						
Uncertain about what to do for your relative	0	1	2	3	4	
Like you should do more for your relative	0	1	2	3	4	
Like you could do a better job of caring	0	1	2	3	4	
<b>When you are with the relative for whom you are caring, how often do you feel:</b>						
A sense of strain	0	1	2	3	4	
Anger	0	1	2	3	4	
Embarrassment	0	1	2	3	4	
Uncomfortable about having friends over	0	1	2	3	4	
<b>How often do you feel that your relationship with the relative for whom you're caring negatively impacts:</b>						
Your social life	0	1	2	3	4	
Other relationships with family and friends	0	1	2	3	4	
Your health	0	1	2	3	4	
Your privacy	0	1	2	3	4	
<b>How often do you:</b>						
Feel you receive excessive help requests	0	1	2	3	4	
Feel all the responsibility falls on one caregiver	0	1	2	3	4	
Fear the future regarding your relative	0	1	2	3	4	
Fear not having enough money to care for your relative	0	1	2	3	4	
Fear not being able to continue caring for your relative	0	1	2	3	4	
Wish to leave the care of your relative to someone else	0	1	2	3	4	
How much does your spouse/loved one depend on you as the caregiver?	0	1	2	3	4	

Please rate your overall level of burden in caring for your spouse/relative:

(0) No burden at all (1) Mild Burden (2) Moderate Burden (3) Severe Burden (4) Extreme Burden

**Interpretation:**

- a. No or minimal burden: 0 to 20
- b. Mild to moderate burden: 21 to 40
- c. Moderate to severe burden: 41-60
- d. Severe burden: 61 to 88



### The Adult Carer Quality of Life Questionnaire (AC-QoL) How to Fill in the Questionnaire

This questionnaire asks you about different aspects of your life as a carer. Please think about your experience as a carer within the last two weeks and please tick the box that applies next to each statement. There are no right or wrong answers; we are just interested in what life is like for you as a carer. The questionnaire shouldn't take more than 10 minutes. Please answer all questions as honestly as you can.

	Never	Some of the time	A lot of the time	Always
<b>Support for Caring</b>				
01. I have a good level of emotional support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
02. My needs as a carer are considered by professionals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
03. I am happy with the professional support that is provided to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
04. I feel able to get the help and information I need	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
05. I have all the practical support I need	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Caring Choice</b>				
06. I feel that my life is on hold because of caring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
07. My social life has suffered because of caring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
08. I feel I have less choice about my future due to caring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
09. I feel I have no control over my own life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Caring stops me doing what I want to do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Caring Stress</b>				
11. I feel depressed due to caring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. I feel worn out as a result of caring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. I am mentally exhausted by caring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. I am physically exhausted by caring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. I feel stressed as a result of caring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



	Never	Some of the time	A lot of the time	Always
<b>Money Matters</b>				
16. I worry about going into debt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. I feel satisfied with my financial situation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. I am able to save for a rainy day	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. I worry about money	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. There is enough money in our house to pay for the things we need	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Personal Growth</b>				
21. I have become a more tolerant person through my caring role	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. Because of caring, I have learnt a lot about myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Because of caring, I feel that I have grown as a person	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. I have experienced many positive things through caring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. I feel that I have become a better person by caring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Sense of Value</b>				
26. I feel valued by the person I am looking after	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. The person I look after respects me for what I do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. The person I look after makes me feel good about myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. I get a lot from the person I am looking after	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. I have a good relationship with the person I am caring for	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Ability to Care</b>				
31. I am satisfied with my performance as a carer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. I can take care of the needs of the person I am caring for	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. I feel I am able to make the life of the person I am looking after better	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. I can manage most situations with the person I care for	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. I am able to deal with a difficult situation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Carer Satisfaction</b>				
36. Caring is important to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. I resent having to be a carer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. I feel frustrated with the person I am caring for	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39. I enjoy being a carer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. I am satisfied with my life as a carer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>