

## Investigating Support for Carers



June 2017

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# Investigating Support for Carers

## About Healthwatch North Somerset

Healthwatch North Somerset's statutory duty and remit, which is laid out in The Health and Social Care Act 2012, is to provide a voice for people who use health and adult social care services, by:

### Influencing

- Giving people an opportunity to have a say about their local health and social care services, including those whose voice isn't usually heard.
- Taking public views to the people who make decisions - including having a representative on the Health and Wellbeing Board.
- Feeding issues back to government via Healthwatch England and the Care Quality Commission (CQC).

### Signposting

- Providing information about health and social care services in the local area. Advising people on where to go for specialist help or information (signposting).
- Helping people make choices and decisions about their care.
- Working closely with other groups and organisations in the local area.

### Our Mission:

By offering all people of North Somerset a strong voice we will improve the quality of local health and social care today and for the future.

## Introduction

Here is a brief overview of the national and local picture for Carers.

Carers UK estimate that nationally 6.8 million people provide unpaid care for a disabled, seriously-ill or older person in the UK. The University of Sheffield 2015 'Valuing Carers Report'<sup>1</sup> says that Carers save the state £132 billion a year, which is close to the cost of a second NHS. They recognise that Carers' contribution to the economy was 7% higher in 2015 than in 2011. Carers UK said those providing high levels of care are twice as likely to have poor health as those without caring responsibilities (2004)<sup>2</sup>.

North Somerset's health and wellbeing strategy document (Joint Strategic Needs Assessment)<sup>3</sup> defines a Carer as someone who provides unpaid care for someone who is disabled, frail, ill, has mental health issues or substance misuse problems. It states that without this support from unpaid Carers many of those individuals who are being cared for would require formal care packages or care home placements.

In 2011 North Somerset's population census<sup>4</sup> identified 22,313 unpaid Carers in the county which at 11.1% of the population is slightly higher than the national average of 10.3%. 21% of those Carers provided more than 50 hours of care each week.

The census identified 326 Young Carers less than 18 years of age, located mainly in Weston-Super-Mare.

Support for Carers was both highlighted and strengthened by the Care Act (2014)<sup>5</sup> which came into force in April 2015 and was updated in April 2016. Its key feature is a duty on all local authorities to offer Carer Assessments to Carers aged over 18. (Appendix 1<sup>6</sup>).

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<sup>1</sup> Valuing Carers report

[www.sheffield.ac.uk/socstudies/...news/valuing-carers-2015-report-1.538603](http://www.sheffield.ac.uk/socstudies/...news/valuing-carers-2015-report-1.538603)

<sup>2</sup> Carers UK 2004 'In Poor Health: The impact of caring on health'

<sup>3</sup> The 2013 North Somerset 'Joint Strategic Needs Assessment' (JSNA) - Carers Executive Summary

[www.n-somerset.gov.uk/wp-content/uploads/2015/11/carers-chapter.pdf](http://www.n-somerset.gov.uk/wp-content/uploads/2015/11/carers-chapter.pdf)

<sup>4</sup> [www.n-somerset.gov.uk/.../statistics-data/census/census-2011](http://www.n-somerset.gov.uk/.../statistics-data/census/census-2011)

<sup>5</sup> Care Act (2014) [www.legislation.gov.uk/ukpga/2014/23/contents](http://www.legislation.gov.uk/ukpga/2014/23/contents)

<sup>6</sup> Appendix Carers Assessments. NHS Choices Carers rights and the Care Act Investigating Support for Carers June 2017

An adult caring for a disabled child (Parent Carer) under the Children and Families Act can ask the Local Authority for an assessment. The Local Authority now has a legal duty to respond and assess their need for support. This covers a parent if they are caring for any amount of time for a child who is blind, deaf, non-verbal, suffering from a mental disorder of any kind, substantially and permanently handicapped by illness, injury or congenital deformity or other disability.

The Children and Families Act <sup>7</sup> also gives Young Carers the right to have Carers Assessments and to be given care plans from 5 years old until 18 years old. These are carried out by Children's Services, North Somerset Council.

The Adult Carers are assessed by Carers Support Alliance who provide information, advice, and signposting and regular support groups for Young and Adult Carers across Weston-Super-Mare, Portishead, Clevedon and Nailsea. Parent Carers Assessments are carried out by North Somerset Council.

The population census for North Somerset 2011 estimates 'due to the national anticipated rise in dementia over the next 5 - 10 years there will be a correlated rise in the number of Carers in North Somerset '.

The services for Carers are provided by Local Council, NHS, Carers support agencies, trusts and charities. National Policy and good practice guidelines are in place to help identify, refer, advise and support Carers. (See Appendix 2 <sup>8</sup> Appendix 3 <sup>9</sup> and Appendix 4<sup>10</sup>).

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[www.nhs.uk/Conditions/social-care-and-support-guide/Pages/carers-rights-care-act-2014.aspx](http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/carers-rights-care-act-2014.aspx)

<sup>7</sup> Children and Families Act (2014)  
[www.legislation.gov.uk/ukpga/2014/6/contents/enacted](http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted)

<sup>8</sup> Appendix 5 Department of Health. Updated 19<sup>th</sup> April 2016. Local Authority duty.  
[www.gov.uk/government/publications/care-act-2014-part-1-factsheets/care-act-factsheets](http://www.gov.uk/government/publications/care-act-2014-part-1-factsheets/care-act-factsheets)

<sup>9</sup> Appendix 4 Carers UK best practice guide for GPs

<sup>10</sup> Appendix 6 National Institute of Health and Care Excellence best practice guidance for supporting Carers

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## Background

Healthwatch North Somerset began this investigation to gather from Carers their opinion and experience of support in North Somerset. The reason we decided to gather the evidence was as a result of:

- Feedback from Carers in North Somerset, subsequently identified by the Healthwatch Prioritisation Panel<sup>11</sup> as a reoccurring theme.
- Information from Carers Trust Phoenix (now Carers Support Alliance)
- The Carers UK ‘State of Caring 2016’<sup>12</sup> findings.
- The Children’s Commissioner 2016 Support for Young Carers report<sup>13</sup>
- An interest in contributing to the Government Carers Strategy in 2017

## Aims and Objectives

The project sought to provide Carers the opportunity to share their lived experience of ‘how and if’ their health and social care needs were being met and the challenges and barriers they faced.

The target population was anyone performing a Caring role in North Somerset; this included elderly carers of adults, adult carers of people with dementia, and carers in work, parent carers, young carers, and carers of people with mental ill health.

We asked what experiences Carers have of the Health and Social Care services they receive or seek to access, rather than the services used by the people they care for.

Healthwatch North Somerset’s channels of engagement are as below:

- Liaise with relevant voluntary sector agencies
- Gather experiences from a diverse range of Carers, both in age and location, using feedback from groups and when attending meetings

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<sup>11</sup> Healthwatch North Somerset Prioritisation Panel is a group of volunteers, Board members and staff who interrogate the monthly feedback reports and identify any specific issues or themes.

<sup>12</sup> Carers UK ‘State of Caring’ 2016 [www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-2016](http://www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-2016)

<sup>13</sup> The Children’s Commissioner 2016 [www.childrenscommissioner.gov.uk/publications/support-provided-young-carers-england](http://www.childrenscommissioner.gov.uk/publications/support-provided-young-carers-england)

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- 🌸 Develop a resource such as a questionnaire focusing on access, quality of care, listening to concerns, provision of information and barriers
- 🌸 Gather quantitative and qualitative intelligence
- 🌸 Provide the questionnaire via our website and promote it widely
- 🌸 Promote the questionnaire by linking it to our website and displaying it on posters in GP surgeries and libraries
- 🌸 Collate findings into an evidence-based report.

## Methods

The evidence gathering for this review was carried out over a number of stages.

In September 2016 Healthwatch North Somerset and Carers Trust Phoenix (subsequently known as Carers Support Alliance) agreed to work together on a project to determine the experience of Carers. They distributed 1800 Healthwatch North Somerset ‘Share Your Story’ leaflets, asking for feedback from Carers. The ‘intelligence’ gathered was added to our monthly Intelligence Reports which are distributed to Service Providers and commissioners. Feedback was also added to a spreadsheet for this report.

We designed two versions of a questionnaire:

- 🌸 one for Adult Carers
- 🌸 one for Children and Young Adult Carers up to the age of 25.

We used Healthwatch North Somerset’s monthly intelligence and the ‘Carers UK Annual State of Caring Survey’ to inform the development of a draft set of questions.

We met with key staff at Carers Support Alliance to talk about the issues Carers have. We received feedback on a draft version of the questionnaire which was then piloted with a group of Carers at an outreach event and the final version was agreed (see Appendix 5 and 6).

The questionnaires were distributed between January 2017 and March 2017 through the following engagement activities:

Street Markets	'Time to Talk' event	Weston Hospital	Leg Clubs in Clevedon & Nailsea	Parkinson Group	Leisure Centres
Sandford Memory Café	Alzheimer 'Care2gether'	Memory Café Nailsea	Supportive Parents	National Autistic Society	Carers Support Alliance
Mental Health Carers	Young Adult Carer groups	Village Agent fairs	Special Educational Needs schools	Senior Community Links	GP Surgeries
Pharmacists	Springboard for U5's with additional needs	Stroke Association	Ups and Downs Club (Children with Downs Syndrome)	Voluntary Action North Somerset	Vision North Somerset
North Somerset Parent and Carers	Care Connect	Avon and Wiltshire Mental Health Partnership Trust	Diabetes Group	Learning Disabilities Partnership Group	North Somerset Council Disabled Children's Team
WAHT Learning Disabilities team	Specialist Community Children's Services	North Somerset Community Partnership	Multi-cultural Friendship Association	Nailsea Disability Initiative	LGBT+ Group
LGBT+ Youth Group	Parish Councils	Youth Clubs	Healthwatch North Somerset website	Smart survey	Libraries

#### Investigating Support for Carers June 2017

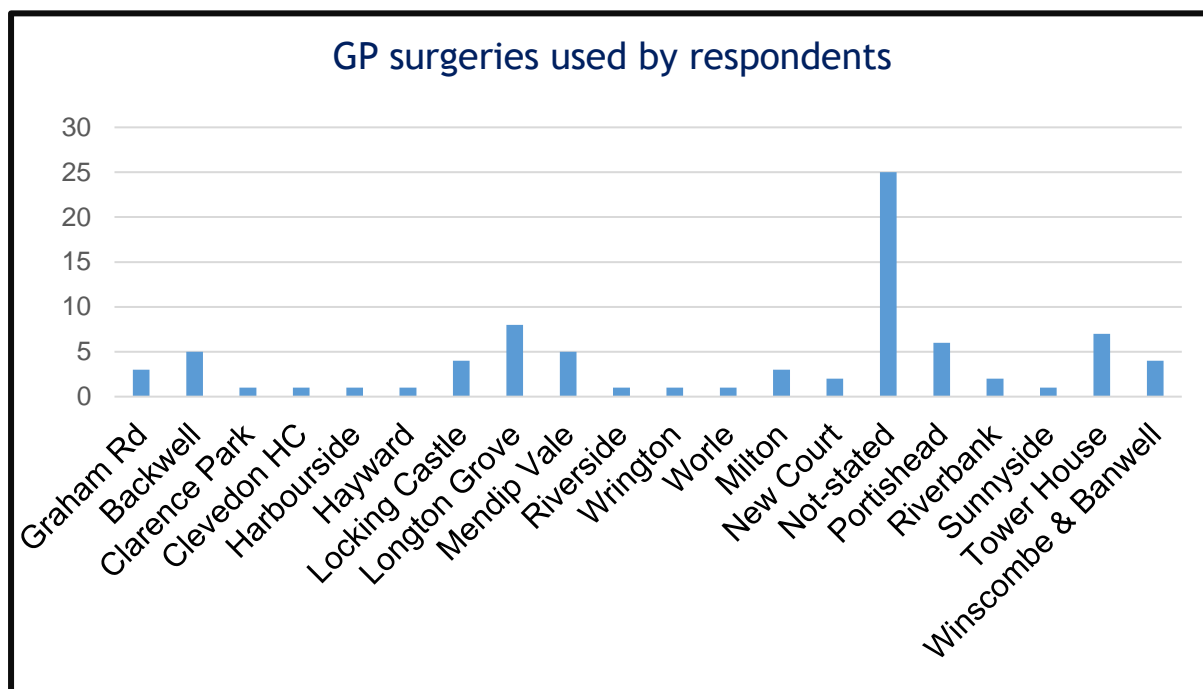
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## Summary of findings

### Demographic information

There were 82 respondents to the questionnaire from across North Somerset. The respondents were registered with the following GP surgeries:



There were 32 Young Carers who responded to the questionnaire and 50 Adults Carers.

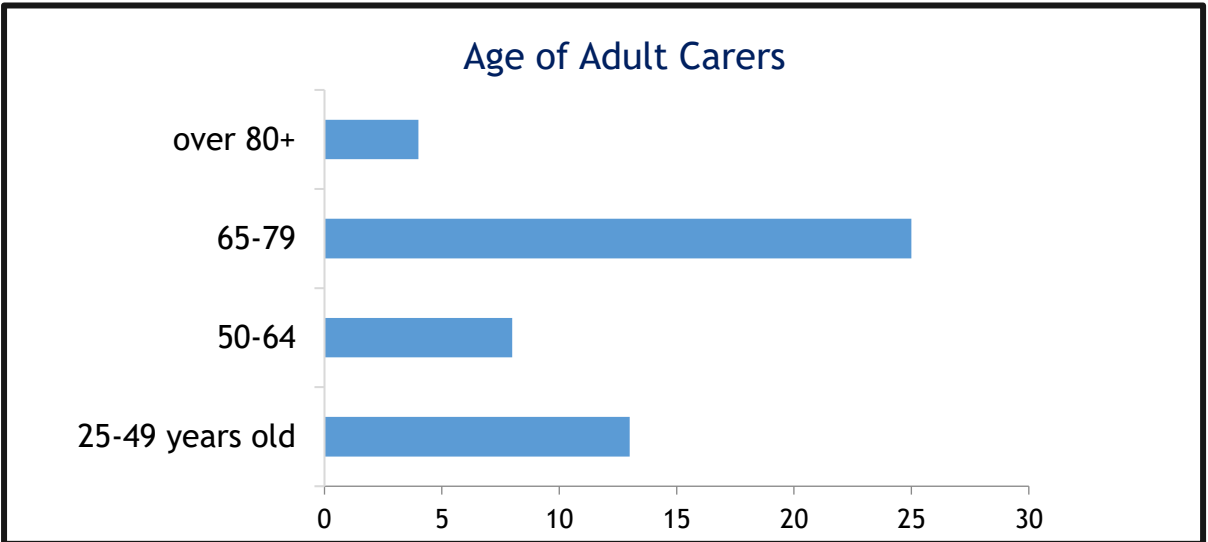
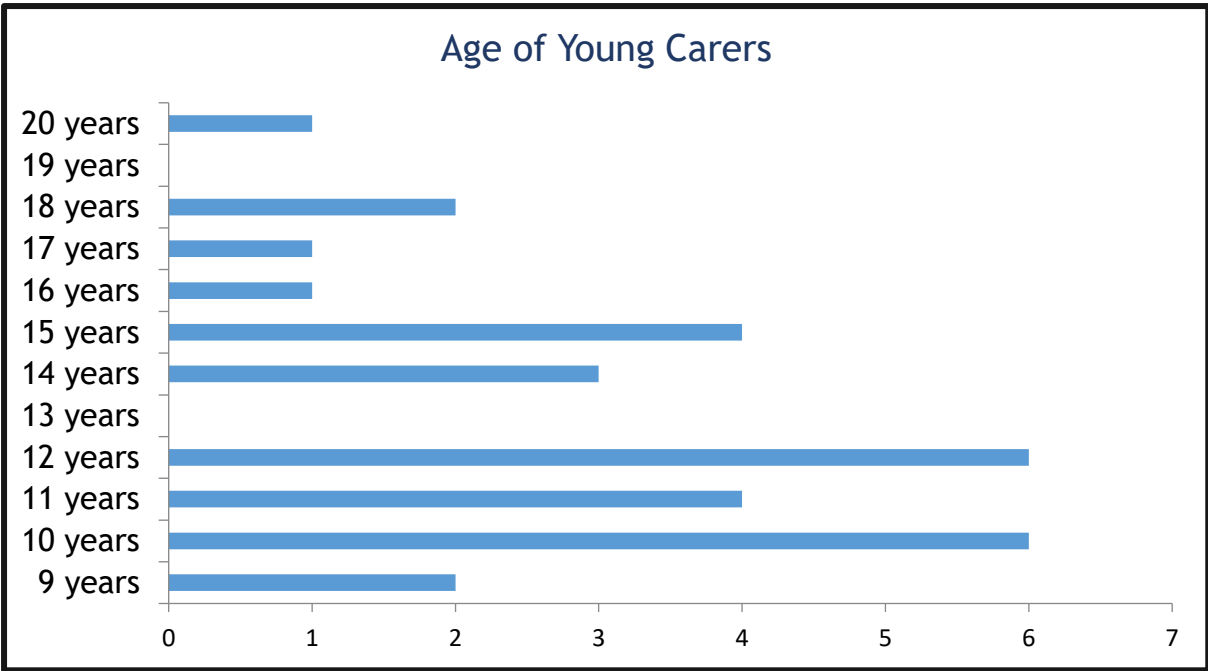
59% of Young Carers were female and 70% of Adult Carers were female.

	Number of Male	Number of Female	Unstated	Total number
Adult Carer	14	35	1	50
Young Carer	5	19	8	32

The age of Young Carers and Adult Carers respondents are detailed in the chart below:

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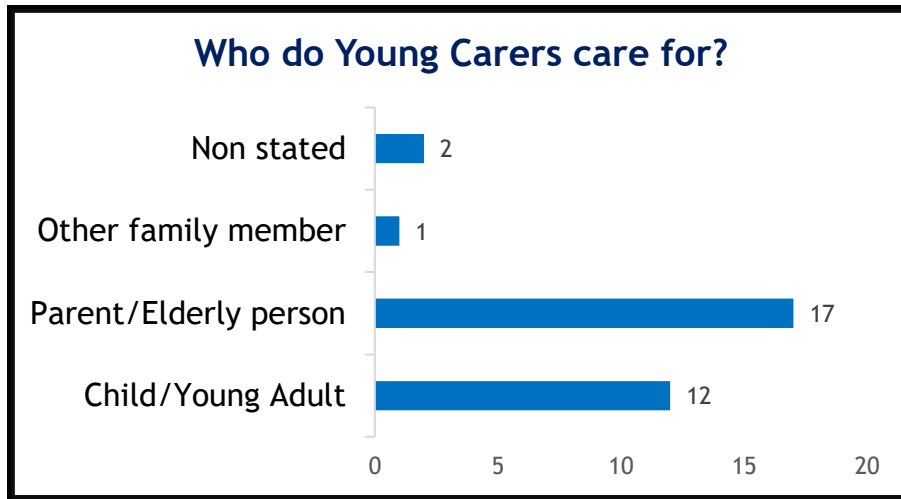


- 🌸 The Young Carers ages ranged between 9 years and 20 years old.
- 🌸 The Adult Carers were predominantly between 65 years and 79 years old.

## Young Carers

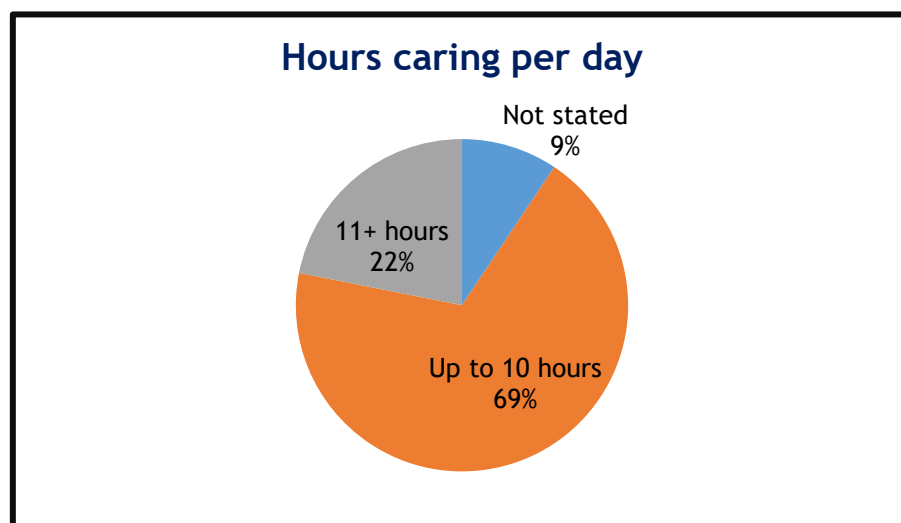
### Who do Young Carers care for?

- 53% of the Young Carers said they cared for a parent or elderly person.
- 37% of the Young Carers said they cared for a child or young adult.



### Daily hours spent caring by Young Carers

When we asked Young Carers to estimate the hours they care, almost 70% of Young Carers said they cared for up to ten hours a day.

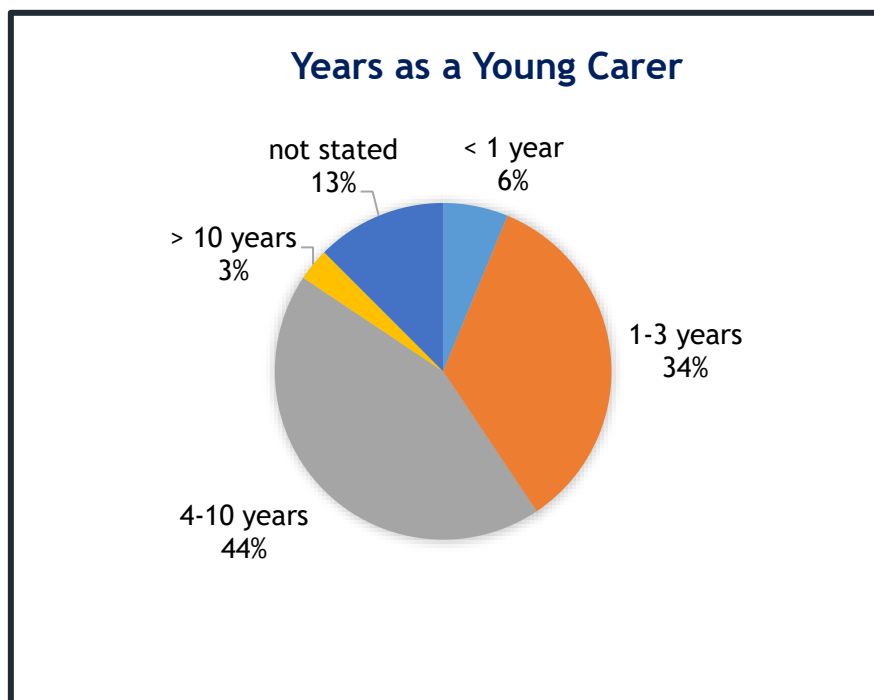


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## Years as a Young Carer

The majority of Young Carers who responded to the questionnaire said they had been a Carer for between 4 and 10 years; while 3% stated they had been a Carer for over ten years.

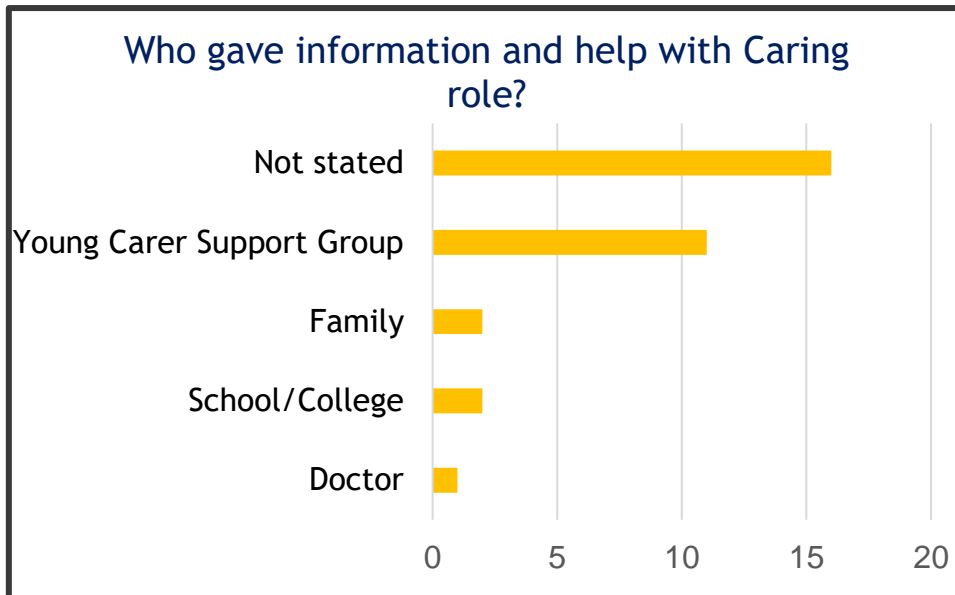


## Getting support

The questionnaire asked Young Carers whether they had been given information about their access to support and help.

63% said they had been given information. We asked where the information and support had had come from. The main place Young Carers received information and support was from Young Carers Support Groups.

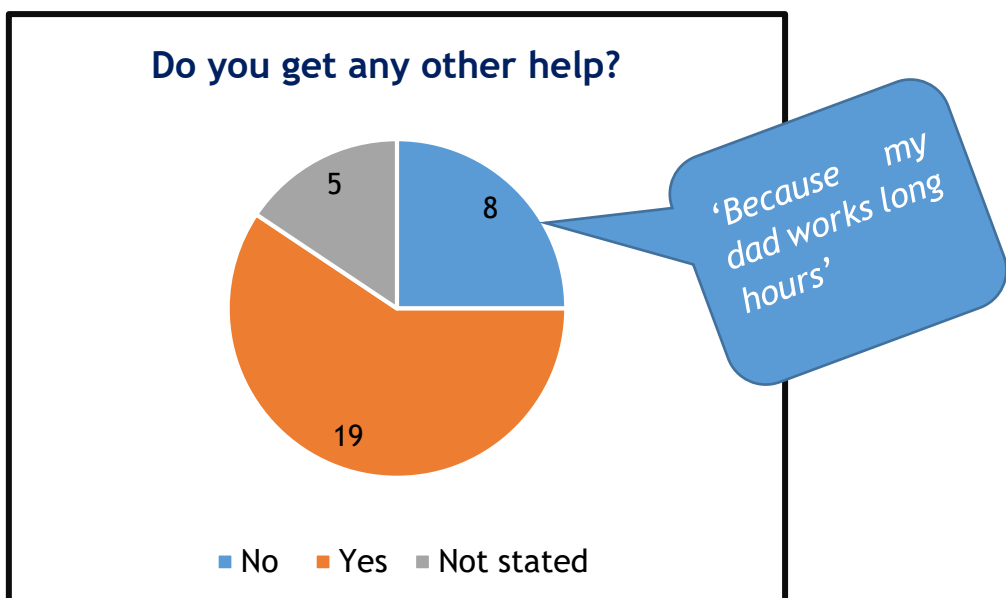
Another 18% said they didn't know and 6% said they had not been given information.



### Where else information and help comes from

When asked what their secondary source of help was, 59% answered, saying they got help from family members, Young Carers Support Groups and local trusts and charities as providers of that help.

25% of Young Carers said they got no other help. Some commented why. One said it is because ‘my dad works long hours’.



When asked for a yes or no to the question ‘Would they like more help?’; 9% of Young Carers said yes.

The kind of help or support they wanted included:

- 🌸 ‘Help with school work and homework’
- 🌸 ‘Help with shopping as I find it stressful’
- 🌸 ‘To keep my phone on in class as I worry about my mum not being able to call me in an emergency.’

## Caring breaks and someone to talk to

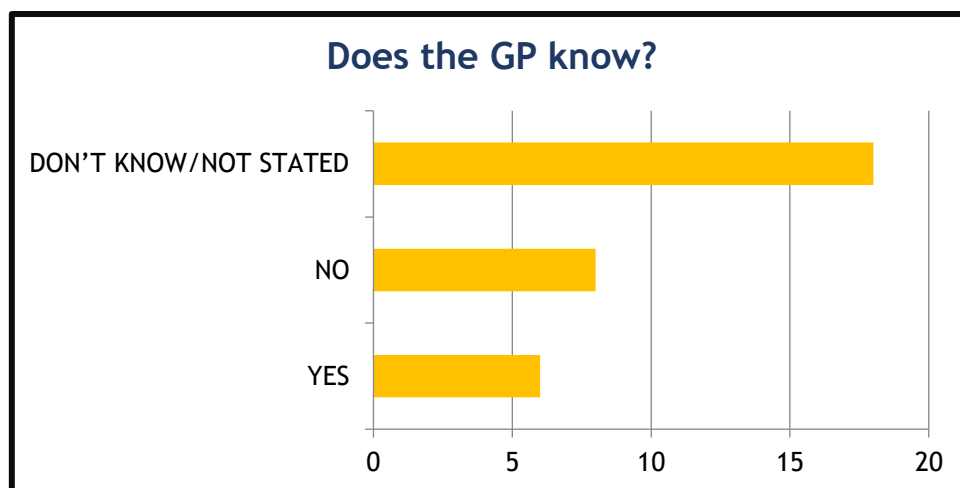
We asked if Young Carers got regular breaks from caring.

75% said they did.

When asked if they have anyone to talk to about their caring responsibilities, 75% of Young Carers said they did.

## GP involvement

We asked Young Carers if their GP knew they were a Carer.



19% (6) of the Young Carers said their GP knew they were a Carer.

25% (8) said the GP did not know.

(See also page 20 of this report)

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## Was school aware?

We asked if their school were aware that they were a carer.

34% of Young Carers were 'not sure' or said 'no' their school did not know they were a Carer.

59% of Young Carers said their school knew they were a Carer.

## What to do when there is a problem

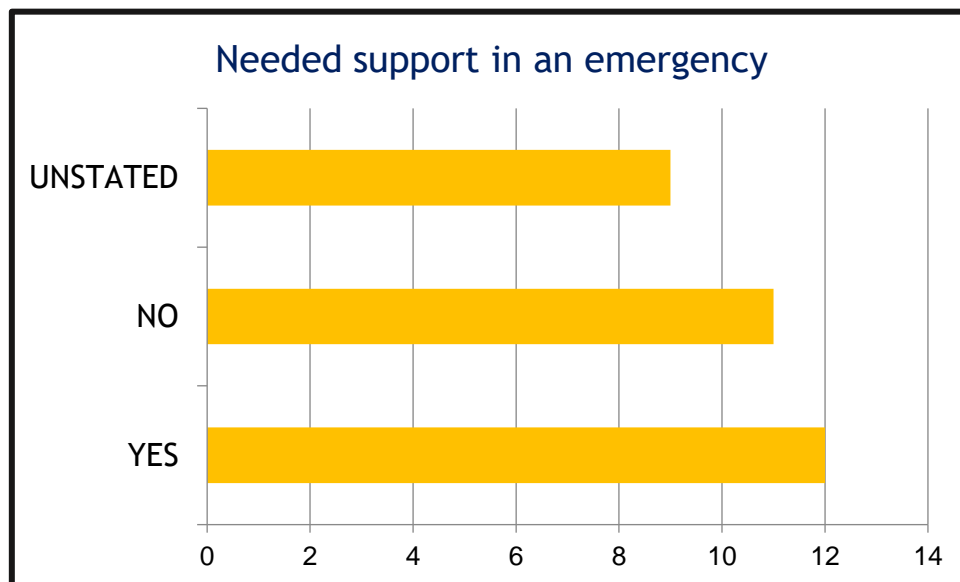
When asked did they know what to do if there was a problem with the person they care for 22% of Young Carers said they did not know.

Do you know what to do if there's a problem?

Yes	22	69%
No	7	22%
Not stated	3	9%

## Support in a family crisis

Over one third of Young Carers said their family had needed support in an emergency.



We asked, at the time they needed support did they get the support they needed? Two (6%) said no, and said they did not know why.

Others who answered yes said they were helped by Young Carers support workers, the 999-emergency service, family members or in one case their best friend's mum.

## Adult Carers

Of the 50 Adult Carers who responded to the questionnaire, 64% indicated they were caring over 40 hours a week.

When asked who they cared for most said they were caring for a Spouse or Partner.

Who do you Care for?	number	% of total
Spouse/Partner	21	42%
Child/Young Person	17	34%
Parent/elderly relative	8	16%
Other family	4	8%

## Carer Assessments

Since April 2015 Carers have had a legal right to receive a Carer Assessment. Those looking after a disabled child can request an assessment of their need for support.

Adult Carers were asked if they had ever received a referral for a Carer Assessment or information about what help and support they might receive.

Of the Carers of a Child/Young Person answering this question, 3 of the 17 or 18% said yes.

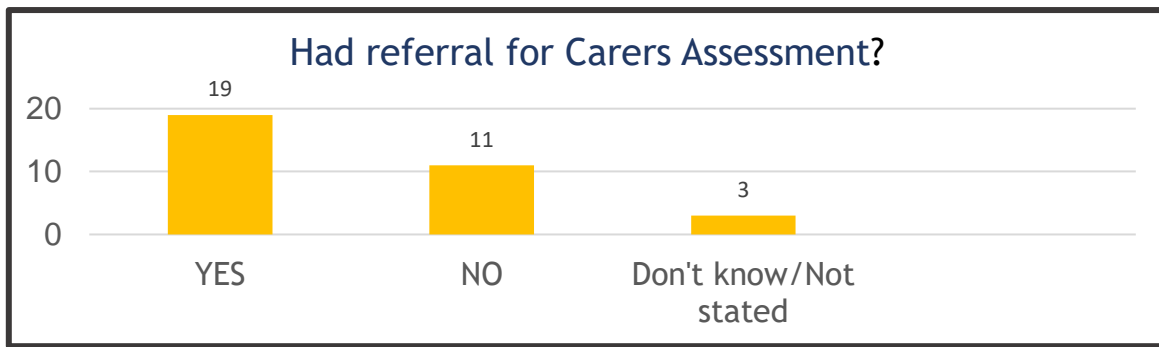
Of the other 33 respondents, Adult Carers who have a legal right to a referral, 58% of them had been referred for a Carers Assessment.

33% had not been referred and another 9% either didn't know or didn't say.

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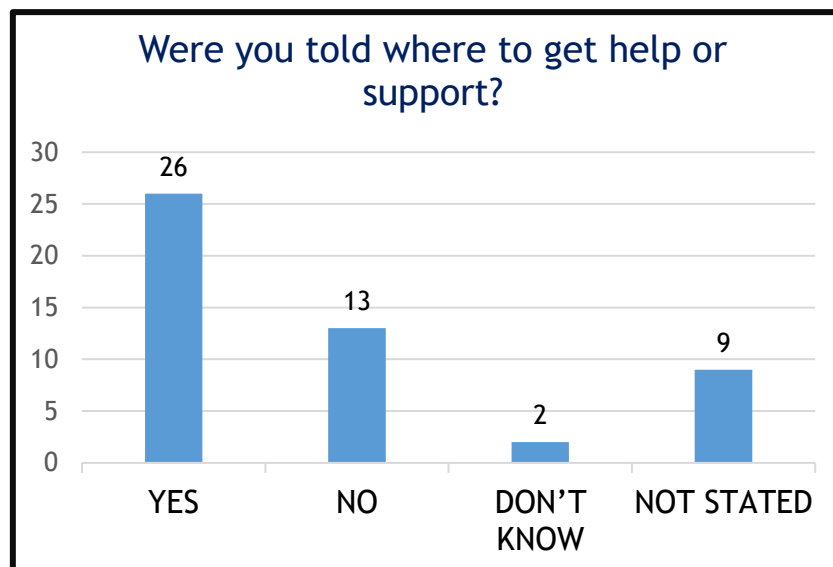




Once a Carer Assessment has been carried out the Local Authority must decide whether the Carers' needs are eligible for support from the Local Authority.

### Adult Carers support

To the question 'Did you receive information about where to get help and support?' The majority said yes (26), although 15 Adult Carers said 'No' or they 'Don't know' if they had received this information.



### Adult Carers experience of support

The Adults Carers' experience of support would be expected to reflect the outcome of their assessment of eligible need.

58% of Adult Carers said 'no' when they were asked if they received any financial support or funded support service to help them carry out their Carers role.

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Of those that receive funded support one Carer said:

**‘A grant from Carers Support Alliance for me to have massage sessions to help relieve stress - very welcome.’**

Another said about getting support,

**‘I don’t know what to do’.**

The 36% who said they received financial support or access to a funded service mentioned:

- Direct Payment
- Disability Living Allowance
- Short Break funding
- Carers Allowance
- Attendance Allowance

Some received services by named providers such as a place in a Day Care Centre run by The Brandon Trust or one-off grants from Carers Support Alliance.

## **Crisis support**

When asked if they had ever needed Crisis support 46% of respondents said no.

16% said they had needed Crisis support.

6% said they did not know they could get Crisis support.

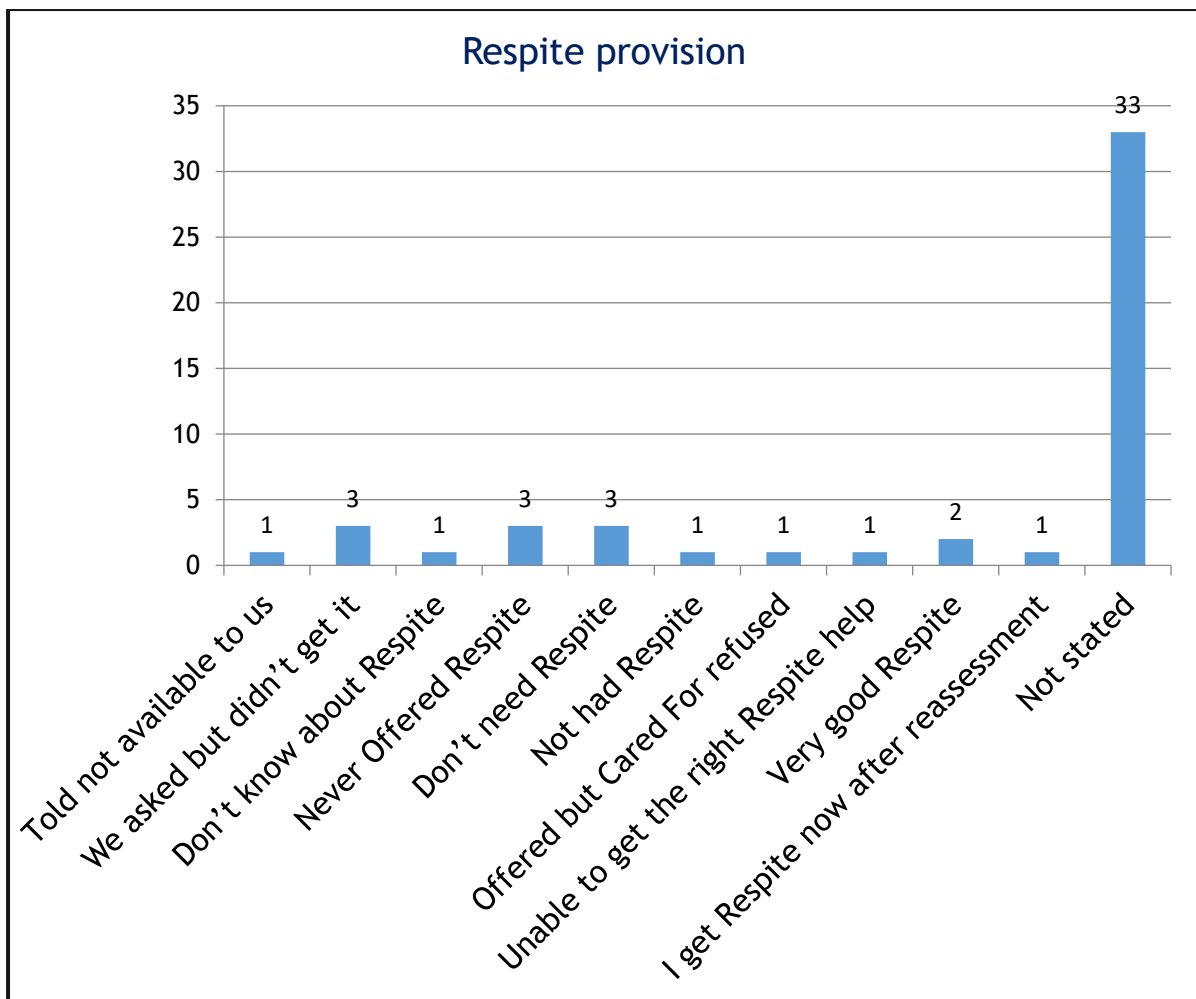
## **Breaks from Caring**

When asked if they got regular breaks from Caring 32% of Adult Carers said they did.

The other 68% either said ‘no’ or did not state if they did.

## **Respite**

When asked if they have needed, been offered or requested support from Respite services 18% of respondents said yes. Their comments on their experience of Respite are in the chart below.

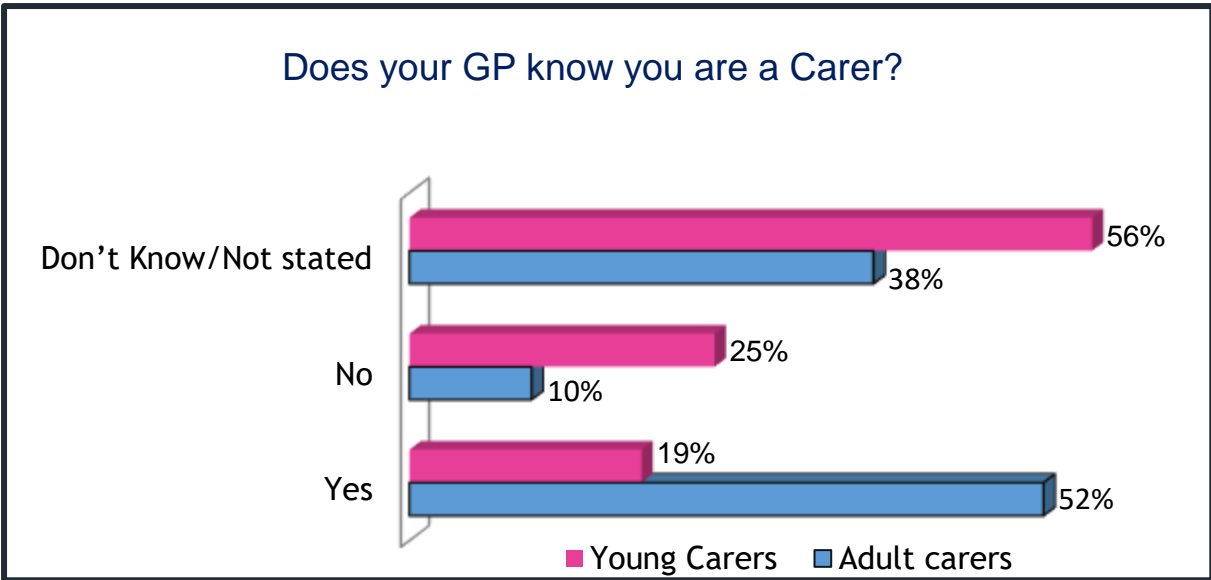


## GP register

GPs have been advised by the Royal College of General Practice<sup>14</sup> keep a register of Carers in order to provide flexible support and information.

52% of Adult Carer respondents said their GP knew they were a Carer. 38% of Adults either didn't know or did not state if their GP knew.

(The chart below also includes Young Carers responses to this question)

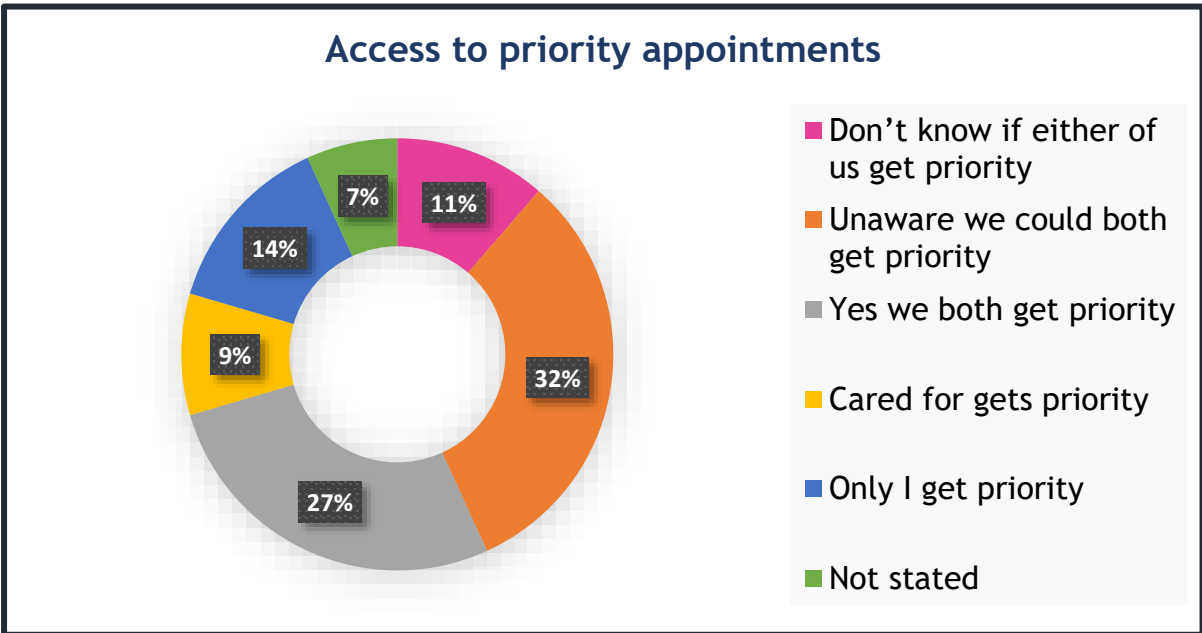


**Access to appointments**

We asked Adult Carers what happened when they or the person they care for needed a Healthcare or GP appointment at their surgery.

11% said it was difficult for both themselves and the person they care for to get an appointment.

32% said they were unaware their GP might be able to offer priority to them as well as the person they care for.



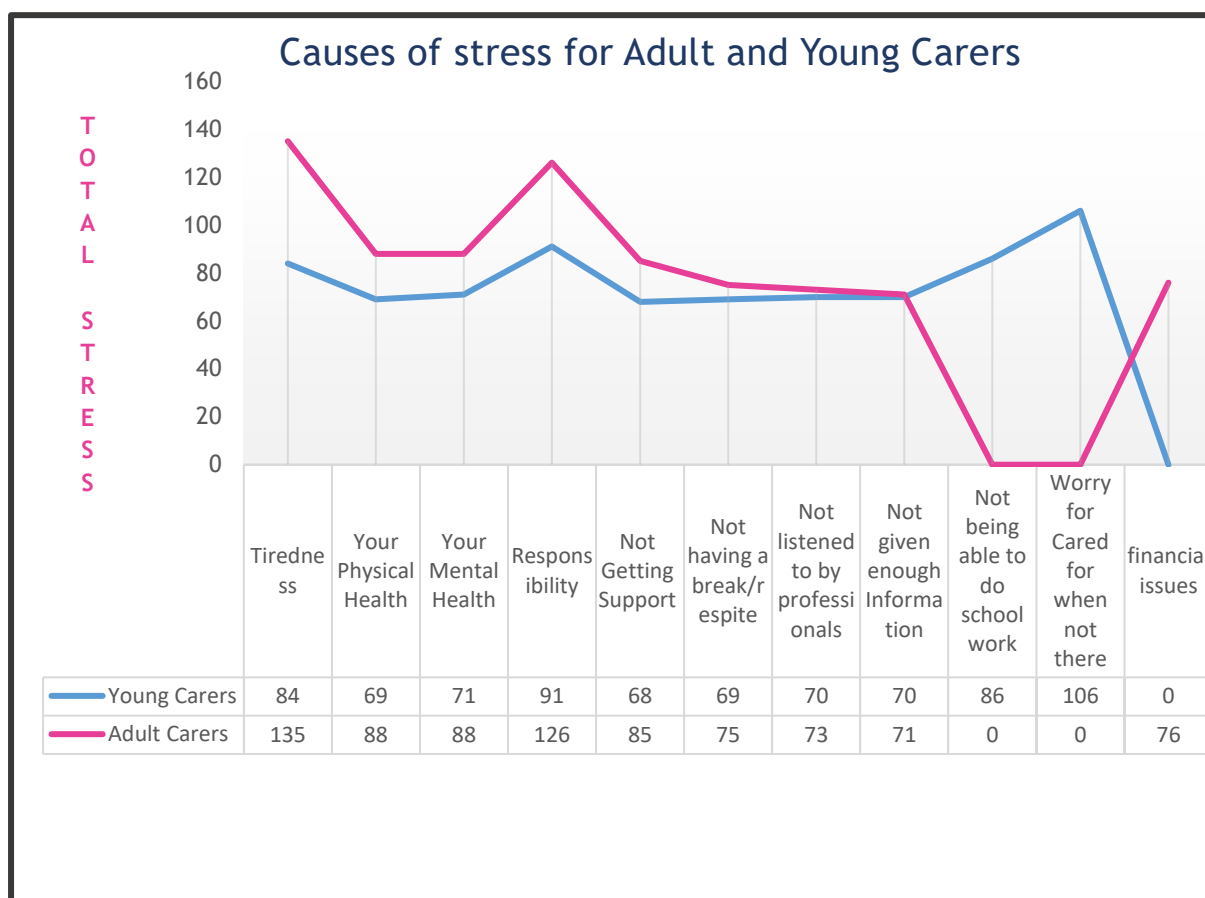
## Causes of stress for both Young Carers and for Adult Carers

We asked both Young Carers and Adult Carers what caused them the most stress as a Carer and to rate it on a scale of 1-5, with 5 being the highest score.

The scores for each of the potential stresses were totalled as shown in the graph below.

Two extra questions about stress of 'school work' and about 'not being at home with them during the day' were asked only in the Young Carers questionnaire.

Stress about Financial Issues was asked only in the Adult Carers questionnaire



### Adult Carers

Adult Carers told us the highest levels of stress from their role was caused by **tiredness**.

The next cause of stress for Adults was the feeling of **responsibility** for the person they cared.

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Equally high came issues of their own **mental and physical health** and of **getting the support they need**.

## Young Carers

Young Carers said **worry for the person they care for**, when they were not with them, caused them most stress.

Their second most stressful issue was the **responsibility of caring**.

Thirdly Young Carers felt stress from needing to find time for **school work**.

Comments from the Young Carers included a few more issues they found stressful:

- 🌸 ‘Me and my mum work together to get my younger siblings out . One has autism and one has special needs. Sometimes my brother can get too much and get out of hand and we sometimes don’t know how to get support and help for him. We feel as if they (professionals) don’t really do much.’
- 🌸 ‘Need help with claim forms...Can’t get GP appointments.’
- 🌸 ‘Being given conflicting information or instructions.’
- 🌸 ‘Don’t need more support as able to talk to people I trust.’

## Conclusion

This review of Carers support highlights the experiences of Carers with different degrees of entitlements and with a range of needs as Carers.

## Young Carers

In 63% of cases Young Carers had been provided with information about where to get support or help. 18% didn’t know if they’d been given this information, and 6% said they had not been given this information. Those who stated their source, mainly said support and help came from the Young Carers Support Groups, with family members also cited.

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The Children's Commission 2016 report on the support provided to Young Carers states that 'emphasis on identification and assessment in legislation, which are resource heavy, may lead to support for Carers being overlooked.'

GPs and Schools' awareness that a Young Person may be carrying out a role as a Carer was lower than expected. 59% said their school knew but 34% said they were unsure that school knew, or said no, the school did not know. 19% of Young Carers said their thought their GP knew they were a Carer.

Young Carers, in 22% of cases, said they did not know what to do if there was a problem with the person they cared for. Asked if they have anyone to talk to about their Caring responsibilities 75% said they did.

Their biggest source of stress for Young Carers was the worry they had for the person they cared for when they were not at home with them. They said they felt stressed by the responsibility of caring and how to get their school work done.

Young Carers Support groups make a positive impact on the Young Carers in North Somerset by providing most of the support and information they receive.

## Adult Carers

Of the Adult Carers entitled under the 2014 Care Act to automatic Carers Assessments, 58% received a referral. 18% of Parent Carers had requested and been referred for a Carers Assessment.

27% of the Adult Carer respondents said both they and the person they cared for were provided with priority status to enable them to attend appointments with their GP. The support offered by GP practices is unclear and was not considered in this review and could be the topic of further investigation. 32% of adults said they did not know that GPs could be flexible and ensure appointments fit in with their needs as a Carer.

We don't know if some Adult Carers may have been eligible for benefits or grants but in this survey 58% of Adult Carers said they received no financial or funded support of any kind.

68% of Adult Carers said they did not get breaks from caring. Some Carers told us they did not know that they could get these. A small number got support from Respite or Crisis Care.

Most Adult Carers said their greatest causes of stress from being a Carer was tiredness and the feeling of responsibility.

## Recommendations

Healthwatch regulations stipulate that service providers and commissioners have a duty to respond to local Healthwatch reports and recommendations within 20 working days, in writing, to acknowledge receipt and to explain what action they intend to take; or if they do not intend to take action they must explain why. (Health and Social Care Act 2012: Addendum to summary report: issues relating to local Healthwatch regulations).

Healthwatch North Somerset recommends the following based on the feedback received by the public in North Somerset.

We believe the following recommendations to be achievable, affordable and evidence based.

1. We recommend that improvements are made to ensure all Adult, Young Carers and Parent Carers needing support are referred for Carer Assessment in line with the Care Act 2014 and the Children and Families Act 2014.

*This review found that of the 17 Carers of a child or young person who responded to the questionnaire, only three had received a referral to a carers assessment. Of the Adult Carers, 33% of respondents indicated they had not been referred for a carers assessment.*

2. We recommend that Carer patients at GP practices are made aware of enhanced access for appointments and that this information is made readily available and accessible for patients in all GP Practices.

*This review found that 52% of Carers said that their GP knew they were a Carer. 32% said they were unaware that they or the person they cared for may be able to have priority appointments at their surgery. 11% said they found it difficult for both themselves and the person they cared for to get an appointment at their GP surgery.*

3. We recommend that information is given to Young Carers of the benefits of providing consent for agencies to share their Carer status with Schools and GPs.

*This review found that 34% of Young Carers did not think their school was aware that they were carers. A key area of stress for Young Carers was worrying about the person they cared for when they were not with them and finding time for school work.*

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4. We recommend that information is widely available and accessible about services, advice, support and eligibility to limit the negative impact of stress on Adult Carers and Young Carers.

*This review found that there were innumerable causes of stress for Adult Carers and Young Carers. The responses from Adult Carers indicated that there was a lack of awareness of the services that they could access despite the majority responding Yes to the question 'Did you receive information about where to get help and support?'*

## Distribution of the Report

This report will be forwarded to the following parties for a response prior to becoming available to the wider public.

1. North Somerset Council
2. North Somerset Clinical Commissioning Group
3. North Somerset Community Partnership (NSCP)
4. Carers Support Alliance

It will also be forwarded to:

5. Healthwatch England
6. NHS England
7. Care Quality Commission

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## Appendix 1: Responses from Commissioners and Providers

### North Somerset Clinical Commissioning Group

The feedback was that the CCG recognise that as we undertake Patient and public engagement and involvement in the future on a BNSSG footprint we must ensure that our policy for reimbursing carers for covering their duties reflects any variation in rates across the area.

Regards

Kathy Headdon  
Lay Member  
North Somerset CCG

### North Somerset Community Partnership



North Somerset Community Partnership  
P O Box 237  
Castlewood  
Tickenham Road  
Clevedon  
BS21 6FW  
Tel: 01275 546800

Eileen Jacques  
Chief Officer  
Healthwatch North Somerset  
3<sup>rd</sup> Floor, The Sion  
Crown Glass Place  
Nailsea  
BS48 1RB

30 June 2017

Dear Eileen

#### Investigating Support for Carers

Many thanks for sending me a copy of the Investigating Support for Carers which is based on feedback from carers during the review carried out by Healthwatch. We welcome this report and the insight it provides into the experience of carers in North Somerset. I was particularly interested in the age range of young carers' and the average hours of care they provided during the day.

I note the 4 recommendations within the report, which relate to carers assessment, information available to support carers, GP appointments and information regarding the benefits of providing consent for agencies to share information. The latter recommendation is specific to young carers.

Whilst the issue regarding GP appointments is not something NSCP can directly influence we recognise our role in ensuring carers are aware of and are able to access services available to them. We recognise the important role played by carers. As such, we are part of the Carer's Alliance and regularly attend their board meetings. We will continue to ensure that operational staff are aware of the services offered by the Carer's Alliance such as the carer's hub and Carer's in Employment Support Service. We will make the Healthwatch Report available to operational staff once it is publically available.

Once again, thank you for the report and raising awareness of the experience of carers within North Somerset.

Yours sincerely

A handwritten signature in black ink, appearing to read 'J. Brown', is written over a light blue horizontal line.

JUDITH BROWN  
Chief Executive

#### Investigating Support for Carers June 2017

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## Alliance Living Support

### RESPONSE TO 'INVESTIGATING SUPPORT FOR CARERS' DRAFT REPORT

#### GENERAL COMMENTS

1. We welcome the research that Healthwatch has carried out to highlight the experiences of adult and young carers in North Somerset. However, in our view Healthwatch should be cautious in extrapolating trends from such small survey samples.
2. More than one third of the adult responders to the Healthwatch survey were 'parent' carers - parents caring for children with special needs - as opposed to 'adult carers caring for another adult'. Services for 'parent carers' and 'adult carers' are very different, and they are governed, commissioned and delivered separately. In our view the distinctions between these different carer populations are under-developed throughout the report content, conclusions and recommendations.
3. Some of the results from the Young Carers survey suggest that using a written questionnaire may not have been the most suitable method for gathering feedback. See specific comments below. We will review the feedback given in the report with our Young Carers.

#### SPECIFIC COMMENTS

4. **Introduction - Page 5:** It is not particularly clear in the introduction that the Carers Support Alliance is a service commissioned by North Somerset Council to provide 1. General advice and support for Young Carers and Adult Carers and 2. Statutory Carer's Assessments for Young Carers and Adult Carers - and that the responsibility for supporting/carrying out assessments for parent carers remains with North Somerset Council.
5. **Methods - Page 7, paragraph 3:** To provide appropriate context, it might be helpful to note that the Carer's Support Alliance is a partnership led by Alliance Homes
6. **Young Carers Getting Support - page 12:** Our understanding is that 100% of the Young Carers who responded to the survey were accessing group and 121 support via The Carers Support Alliance. By definition, all Young Carers who responded were already receiving information, advice and support. The finding that '*only 63% said that they had been given information about what help they can get*' suggests that some context to this question may have been lacking. We will review this finding with our Young Carer Groups.
7. **Adult Carers (Carers Assessments) - Page 16 & 17**  
The mixture of percentages and numbers makes this section (and the accompanying bar graph) difficult to interpret. Page 17: '*Once a carers assessment has been carried out the Local Authority must decide whether the carers needs are eligible for support from the Local Authority.*' Refer to our earlier comments re the different commissioning arrangements for parent carers and adult carers.
8. **Adult Carers Support - Page 17** There is no differentiation between adult carers and parent carers in this section.
9. **Adult carers experience of support - pages 17 - 19:** '*The Adult carers' experience of support would be expected to reflect the outcome of their assessment of eligible need.*' We are not sure what this sentence means. These sections, and the remainder of the report (eg in Conclusions) are characterised by a lack of differentiation between 'parent carers' and 'adult carers'
10. **Recommendations relevant to The Carers Support Alliance**  
**Recommendation 1:** We will continue to widely publicise the availability of Carers Support Alliance services directly to carers, and indirectly to other agencies and professionals who work with them. NB Whilst we always encourage adult carers to exercise their right to a formal carers assessment, not all carers wish to exercise this right.  
**Recommendation 3:** We will continue to encourage every Young Carer we support to engage meaningfully with school to receive the support and help s/he needs. (NB Research carried out by The Carers Trust [https://professionals.carers.org/sites/default/files/supporting\\_young\\_carers\\_in\\_schools\\_-\\_an\\_introduction.pdf](https://professionals.carers.org/sites/default/files/supporting_young_carers_in_schools_-_an_introduction.pdf) suggests that the level of schools awareness of Young Carers may be slightly better in North Somerset than the national average). Engaging schools meaningfully remains our highest priority in helping to identify previously hidden Young Carers. Children in Need funding has recently been re-secured (until January 2019) to help us continue to meaningfully engage primary and secondary schools to identify and appropriately support Young Carers.

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**Recommendation 4:** We will continue to offer and publicise a professional, free counselling service for adult carers in North Somerset who may benefit from it. This service is 100% funded through charitable donations. We have plans to extend our counselling service to Young Carers in the near future.

## North Somerset Council

### **North Somerset Council feedback re: Healthwatch report ‘Investigating Support for Carers, June 2017’**

This is the response of North Somerset Council to the draft Healthwatch report ‘Investigating Support for Carers, June 2017’. The council welcomes feedback from carers on the support available to them and the work that Healthwatch does to engage with a range of carers in our community. This enables development and improvement of existing supports and helps us to plan for the future.

#### **Comments on the report**

It is positive to see (on page 14) that 75% of the young carers who responded get a break. Providing information and advice on what is available is a significant theme in the report for adult and parent carers and requires the council to continually ensure that we maintain efforts to do so in ways which carers find useful.

There are also a number of issues which arise in the above Healthwatch report to which the council wishes to draw attention prior to responding in detail on pages 4-6 of this document to the recommendations made by Healthwatch on pages 24-5 of the report.

#### **Sample size**

It is positive to see that Healthwatch gained responses from 32 young carers. As the Census 2011 identified 326 young carers in North Somerset this potentially represents 10% of the young carers in the area.

The adult care aspect of this report though is based on a sample group of 50 responses. This represents 0.002% of the 22,000-plus adult carers in North Somerset overall. The council acknowledges that this report is representative of the experiences of those 50 adult carers but do not consider that this is a large enough sample group for the report findings to be regarded as representative of the wider adult carer population.

#### **Terminology**

The term ‘adult carers’ is used throughout the report to refer to a) adults caring for adults as well as b) parent carers of disabled children. As the situations and needs of these two groups of carers can be very different, merging them together in this report as ‘adult carers’ could potentially mask the differences and the impact of them.

To group them together does not reflect that they are covered by different legislation which impacts the council’s duties and responses to the two groups. Due to different legislation:

- i) they do not receive the same assessments of their needs,
- ii) adults caring for adults are covered by an eligibility criteria whereas parent carers are not, and
- iii) the council’s duty to meet their identified needs varies.

Consequently it is difficult to use the report to identify particular strengths or gaps in support for these two different types of carers which could improve their experience of caring.

#### **Different types of assessment and support**

To expand further, the report does not differentiate between the types of carers’ assessments and carers’ entitlements under relevant legislation as follows:

- i) parent carers are entitled to a ‘parent carer’s needs assessment’ under the Children and Families Act 2014 and a consideration as to whether their needs can be met by the provision of services under Section 17 of the Children Act 1989;
- ii) young carers are entitled to a ‘young carer’s needs assessment’ under the Children and Families Act 2014 and a consideration as to whether their needs can be met by the provision of services under Section 17 of the Children Act 1989;

#### **Investigating Support for Carers June 2017**

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iii) and adult carers of adults are entitled to a 'carers's assessment' under the Care Act 2014 and that their identified needs are met if they reach the eligibility criteria for carers within the Act, along with a support plan to indicate how these eligible needs will be met.

The term 'carer's assessment' is used within the report to cover all of the above assessments when in fact the legislation which applies to each group varies the duties which the council has to each. There is the risk that misunderstandings could occur as a result of this.

### Clarifications

The council recommends that the following points are clarified in the document:

1. On page 4 paragraph 3 refers to North Somerset's health and wellbeing strategy document as being the Joint Strategic Needs Assessment. However, these are in fact two separate documents. The JSNA is an assessment of local need which is used to inform the People and Communities Strategy. It is this People & Communities Strategy which constitutes the local health and wellbeing strategy.

2. On the same page, paragraph 6 states in reference to the Care Act that *'Its key feature is a duty on all local authorities to offer Carer Assessments to Carers aged over 18'*. This duty is one of the Act's key features but not the only one as the Act pulls together many decades of legislation for the cared-for person too. Also the duty is with regard to carers aged 18 and over, rather than *'aged over 18'*. The above statement would suggest that parent carers are included so long as they are over 18. To clarify, this Care Act duty only applies to carers aged 18 and over who are looking after other adults. It does apply to parent carers at the time of their child's transition to adult care services but otherwise parent carers looking after a disabled child are covered by the Children and Families Act 2014.

3. On page 5 in paragraph 1 it would be helpful to clarify that the assessment that a parent carer can request from the council under the Children and Families Act is a 'parent carer's needs assessment'. In the same paragraph the description of the child's needs uses terminology which is not generally used today such as the word 'handicapped'. It would be constructive to update the terminology used in this section.

It would also be helpful to add that the parent carer's needs assessment is usually combined with the assessment of their child's needs, rather than being a separate assessment. This would help to manage expectations as some parent carers may assume their assessment would be separate as a matter of course. Having a combined assessment may have impacted on some parent carers' perception as to whether or not they have had an assessment of their own support needs. In evaluating responses from parent carers to the Healthwatch questionnaire it is worth considering whether some who indicated that they had not received an assessment, or were not sure whether they had received an assessment, had in fact received a combined assessment.

4. On the same page in paragraph 2 it states that Young Carers have the right to a Carers Assessment under the Children and Families Act. It would be helpful to clarify that they have a right to a 'young carers' needs assessment' under this Act, as this is different to a 'carers assessment' under the Care Act.

5. This paragraph of the report also refers to young carers' right to be given care plans from 5-18 years old. Could the report please reference the source of this information as the Children and Families Act gives councils a duty to assess and consider young carers' needs but does not confer a duty to meet these nor to provide a care plan?

6. This paragraph also states that young carers' needs assessments are conducted by Children's Services within NSC. They are in fact carried out by the Young Carers Support Service at Carers Support Alliance. This is a service which the council commissions from Alliance to do this statutory work on our behalf.

7. In paragraph 3 where it is stated that adult carers are assessed by Carers Support Alliance it would be helpful to add by way of explanation that this service, along with the info/ advice and support groups they provide, is funded by the council for them to deliver this work on our behalf.

8. On page 7 under Methods, it is stated that the report is based on two versions of a questionnaire, one for adult carers, one for young carers. Due to the fact that adult carers of say, someone with a mental health issue or someone with dementia, and parent carers of a disabled child may not have similar needs, it would have been useful to have some way within the report of identifying their specific experiences in order to highlight any differences in support to adult and parent carers. As they are grouped together this gets lost.

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9. On page 17 in discussing findings regarding parent carers and adults caring for adults the report states: *'Once a Carers Assessment has been carried out the Local Authority must decide whether the Carers' needs are eligible for support from the Local Authority'*. This is true, under the Care Act, for adults caring for adults. However, for parent carers and young carers under the Children and Families Act there is no eligibility criteria imposed by law and no legal duty for the council to meet needs. The Act gives the council the responsibility to consider their assessed needs and whether any of these can be met by services under Section 17 of the Children Act, i.e. 'children in need' services. 10. Also on page 17 it states that *'The Adult Carers' experience of support would be expected to reflect the outcome of their assessment of eligible need'*. As indicated in point 9 above, the concept of 'eligible need' applies to adult carers of adults but not parent carers. It would be helpful to draw that distinction in the report here so as to eliminate the potential for misunderstanding.

### Response to Healthwatch recommendations

The council's responses to the Healthwatch recommendations on pages 24-5 in the report are below.

1. Healthwatch says: *We recommend that improvements are made to ensure all Adult, Young Carers and Parent Carers needing support are referred for Carer Assessment in line with the Care Act 2014 and the Children and Families Act 2014.*

NSC's reponse: The report states on page 16 that of the 33 adult carer respondents 11 (33%) had not been referred for a carer's assessment and 3 (9%) didn't know or didn't say. During the assessment of any adult for care and support the assessor must identify whether there is a carer. They must offer the relevant assessment and record if the carer accepts or declines this.

It should be noted that a significant number of carers who are offered a carer's assessment decline the offer and therefore of those 11 who stated that they had not been referred, for some at least this may have been their choice; the report does not extrapolate this.

NSC would like to see all adult, young and parent carers receiving their relevant carer's assessment. Since April 2017 the council has improved information to carers, including information about and access to carers assessments by launching its Carers Hub in April 2017. This is an online resource for adult carers within the North Somerset Online Directory which provides carers with the opportunity a) to register with the council as a carer which enables us to keep them up to date with information; b) to search for relevant information and to collate a bespoke information brochure to meet their needs; and c) to complete a carer's assessment online which would be forwarded to Carers Support Alliance for further follow-up. <http://nsod.n-somerset.gov.uk/kb5/northsomerset /directory/carers . page>

The council has gathered a database of adult carers who participated in the local response to the national Survey of Adult Carers in England (2016) who are willing to take part in further research. We will approach this group to ask for ideas and suggestions as to how we can make further improvements to our information to adult carers and ensure that they are aware of their right to an assessment.

The latest edition of the council's North Somerset Life magazine features a whole page on young carers, by the council and the Carers Support Alliance's Young Carers Support service, to raise awareness of their issues and the range of support available. By linking in to this young carers will also get access to information and advice.

We recognise that we need to improve the information we provide to parent carers about their right to a parent carer's needs assessment. Amongst the measures we will take is that we will put information about this for parent carers onto the North Somerset Online Directory's Local Offer pages.

We will put a full page article in a forthcoming edition of North Somerset Life magazine, which goes to every home in North Somerset, to promote adult and parent carers' awareness of their rights and the information and support that is available.

### Investigating Support for Carers June 2017

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**2. Healthwatch recommends:** *'that Carer patients at GP practices are made aware of the enhanced access for appointments and that this information is made readily available and accessible for patients in all GP Practices.'*

NSC's response: The council will work with the local NHS Clinical Commissioning Group (CCG) to encourage GP practices to promote enhanced access for appointments and information about this. We will include information on this on the Carers Hub and in a future edition of North Somerset Life magazine.

**3. Healthwatch recommends:** *'that information is given to Young Carers of the benefits of providing consent for agencies to share their Carer Status with Schools and GPs.'* NSC's response: The council will work with its commissioned Young Carer Support service at Carers Support Alliance to ensure young carers receive information on the benefits of this.

**4. Healthwatch recommends:** *'that information is widely available and accessible about services, advice, support and eligibility to limit the negative impact of stress on Adult Carers and Young Carers'*.

NSC's response: Please see our response to Healthwatch's first recommendation above. The council will promote information on the North Somerset Carer's Hub, North Somerset Life magazine. We will seek the views of adult carers via our database of carers following the Carers Survey, and will seek the views of young carers via the Young Carers Support service at Carers Support Alliance. We will also request that GP practices hold information leaflets on the Carers Support Alliance which can provide further detailed information in response to a carer's specific needs.

**Kathryn Benjamin, Carers Lead, North Somerset Council, 04.07.2017**

## Appendix 2: Acknowledgements

Healthwatch North Somerset would like to thank the public of North Somerset for providing feedback on their experiences of Caring, in particular we would like to thank the following for their invaluable support:

All the people involved in the groups and organisations noted on page 8 of this report.

Carers Support Alliance for supporting the development of this review.

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## Appendix 3 Useful Information and Support

- 🌸 Alliance Living 'Home from Hospital' Carers Support Service  
03000 120120
- 🌸 Alzheimer's Association  
01278 663927 / [www.alzheimers.org.uk](http://www.alzheimers.org.uk) Carers2gether Group /  
Sue.Riley@alzheimers.org.uk
- 🌸 Avon and Wiltshire (Mental Health) Partnership Trust  
[www.awp.nhs.uk/](http://www.awp.nhs.uk/)
- 🌸 Care Connect  
01275 888 801 - Adults / 01275 888 808 - Children and Young People /  
[care.connect@n-somerset.gov.uk](mailto:care.connect@n-somerset.gov.uk)
- 🌸 Carers Support Alliance Adults & Young People  
03000 120120 (option 3) / [www.alliancehomesgroup.org.uk](http://www.alliancehomesgroup.org.uk)
- 🌸 Carers UK  
0207 3784999 / [info@carersuk.org](mailto:info@carersuk.org)
- 🌸 Diabetes Groups South West  
01823 448260 / [South.West@diabetes.org.uk](mailto:South.West@diabetes.org.uk)
- 🌸 Leg Club  
Gordano Clevedon 01275 873588 / Nailsea 07954 302498
- 🌸 Memory Café  
Nailsea 07580 716510
- 🌸 Multi-Cultural Friendship Association  
[www.mfa-wsm.org.uk](http://www.mfa-wsm.org.uk)
- 🌸 Nailsea Disability Initiative  
01275 812183
- 🌸 North Somerset Council  
01934 888 888 / [www.n-somerset.gov.uk](http://www.n-somerset.gov.uk)
- 🌸 North Somerset National Autistic Society


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01934 412575

 North Somerset Parent Carers  
07852 660 670 / [admin@nsparentcarers.org.uk](mailto:admin@nsparentcarers.org.uk)


 LGBT+ Forum  
01934 410192


 Parkinson's UK  
Nailsea 01179 501 477 or 01275 855 524 / Weston-super-Mare, 0844 225 3694  
/ [bvso.southwest2@parkinsons.org.uk](mailto:bvso.southwest2@parkinsons.org.uk) / [www.parkinsons.org.uk](http://www.parkinsons.org.uk)

 Sandford Memory Café  
01934 414 213

 Senior Community Links  
<https://seniorcommunitylink.uk/>

 Springboard Opportunities Group  
01275 341113 / [www.springboardweb.org.uk](http://www.springboardweb.org.uk)

 Stroke Association Network  
01275 870328 / [verity.aldous@stroke.org.uk](mailto:verity.aldous@stroke.org.uk)

 Supportive Parents  
0117 9897725 / [www.supportiveparents.org.uk/](http://www.supportiveparents.org.uk/)

 Ups and Downs Club  
01278 691 100 / [info@upsanddowns.fsnet.co.uk](mailto:info@upsanddowns.fsnet.co.uk)

 Voluntary Action North Somerset  
01934 416486 / [www.vansweb.org.uk/](http://www.vansweb.org.uk/)

 Village Agents (West of England Rural Network)  
01275 888803

## Appendix 4: Carers UK / Carers Assessments

These Carer Assessments are the basis of a Care Plan for Carers and are the vehicle in-law through which Carers' physical and emotional wellbeing is recognised and supported. Carers no longer have to care for a specific amount of time to qualify and don't need to ask for this assessment, it should be offered. Carers are now seen as individuals who have the right to be supported themselves.

In 2011 Carers UK produced a best practice guide for GPs which suggested offering the following:

- flexible appointment times for Carers
- priority for first appointments of the day to minimise waiting
- Consecutive appointments with the person they care for
- annual health checks and flu vaccinations
- home visits
- Carers' champions in GP practices to identify carers, record carer status and offer support

In 2016 Shadow Carers Minister Barbara Keeley MP spoke of the role the health service must play in identifying Carers and stated that "the NHS is nearly always the first point of contact for Carers as they begin caring, and so is best placed to identify them".

Carers UK

<http://www.carersuk.org>

## Appendix 5 Department of Health:Care Act 2014

Department of Health, Care Act 2014 Factsheet on general responsibilities of local authorities; prevention, information and advice, shaping the market of care and support services.

*‘Local Authorities must provide or arrange services that help prevent people developing needs for care and support or delay people deteriorating such that they would need ongoing care and support.’*

They must consider identifying Carers in the area who might have support needs that are not being met.

*‘In taking this role Local Authorities need to work with their communities and provide or arrange services that help to keep people well and independent. This should include identifying the local support and resources already available, and helping people to access them.’*

<https://www.gov.uk/government/publications/care-act-2014-part-1-factsheets>

## Appendix 6 NICE

National Institute of Health and Care Excellence

### **NICE Guidelines**

#### **Referral for Carer Assessments by GP:**

It is important that the practice has a protocol for the identification of carers and a mechanism for the referral of carers for social services assessments.

#### **Carers of people with Dementia:**

GP practices to record the name and contact details of Carers of people with dementia with the aim of improving communication between all those involved in a person with Dementia's care, including within the practice and with other teams.

[www.nice.org.uk](http://www.nice.org.uk)

# Appendix 7 Questionnaire: Adult Carers

## Adult Carers Questionnaire

The details you have supplied in this questionnaire will be used anonymously in our report, we are collating information to inform service providers of their user’s experience of being a Carer in North Somerset.

The report will help to shape carer services to meet the needs of local people.

**Town/Village/Area you live in** .....

**GP Surgery/Health Centre Attended**.....

**Your Age**.....

**Your Gender**.....

- 1) Can you tell us who you care for? (please tick all answers that apply)**
  - a) Spouse or a Partner
  - b) Child/Young Adult
  - c) Parent/Elderly Relative
  - d) Other Family Member
  - e) Neighbour/Friend
  - f) Other.....
  
- 2) Can you tell us how long you have been a Carer? (please tick one answer only)**
  - a) Under a year
  - b) Between 1 and 3 years
  - c) Between 4 and 10 years
  - d) Over 10 years
  
- 3) Roughly how many hours a week do you provide necessary Care? (please tick one answer only)**
  - a) Up to 10 hours
  - b) 11 - 20 hours
  - c) 21 – 40 hours
  - d) Over 40 hours
  
- 4) Have you been referred for a carer’s assessment? (please tick/complete which answer apply)**
  - a) **IF YES:** Could you tell us who referred you for an assessment or gave you information about the carers assessment  
.....
  - b) **IF NO:** Could you tell us why?  
.....
  - c) **NOT SURE** If I have been referred for a carer’s assessment
  
- 5) Have you received information about what help and support you and the person you are caring for might be able to access? (please tick/circle/complete which answers apply)**
  - a) **IF YES:** Who gave you the information.....
  - b) **IF NO:** How did you/do you find out information.....
  - c) **I DON’T KNOW** what support is available because of the following reasons  
I haven’t been given any information / I don’t know how to find information

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6) Do you receive financial support to help you carry out your caring role? (please tick/circle/complete which answers apply).

a) If YES: Can you state what financial support do you get?.....

b) If NO: Can you tell us why?

Ineligible / don't know about financial support available / self-funding / unable to fill in forms to apply / preferred not to say / other reason.....

7) Do you receive a funded support service to help you carry out your caring role? (please tick/complete/circle which answers apply).

a) If YES:

Service Name.....

Quality of support: Very good / Satisfactory / Poor / unacceptable

b) If NO: can you tell us why you don't get support by circling the appropriate answer below

Ineligible / didn't know about support available / self-funding / other reason .....

Please use this box if you have any further comments about funded support services.

8) Do you know if you are registered as a carer with your GP? (please tick/complete which answer apply)

a) YES: My GP/healthcare professional has talked to me about this service and has registered me as a carer

b) NO: My GP/healthcare professional has not registered me as a carer (please can you tell us below the reason why if known).....

c) I DIDN'T KNOW I could be registered as a carer with my GP/healthcare professional

d) I AM NOT SURE If I am registered as a carer with my GP/healthcare professional

9) Do you and the person you care for have priority status for GP/healthcare appointments? (Please tick appropriate answer)

a) Priority GP/healthcare appointments given to both myself and the person I care for

b) Priority GP/healthcare appointments given to the person I care for but not for myself

c) Priority GP/healthcare appointments given to me but not the person I care for

d) Access to GP/healthcare appointments difficult to get for both myself and the person I care for

e) Unaware that carers and the people they care for should be given Priority for GP/healthcare appointments

f) I Don't know if the person I care for or myself get priority for GP appointments

10) Have you been informed about crisis support? (please circle one answer) YES / NO

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**11) Have you ever needed or requested crisis support? (please tick/circle/complete as appropriate)**

- a) **If YES** and you have received a crisis service support, could you tell us about the quality and response of the service:

**Name of crisis service**.....

I. **Quality:** Very good / satisfactory / poor / unacceptable

II. **Timing:** Immediate / timely / not timely / too late

III. **Funding:** Fully funded / part funded / not funded / other

- b) **If you have needed or requested crisis support but have not received the service** can you tell us why?

Ineligible / cost / refused the crisis support offered / Didn't know I could get crisis support / other.....

Please use this box if you have any further comments about your experience of crisis services.

**12) Have you ever asked for/been offered respite care? (please tick/complete/circle all answers that apply)**

- a) **YES**, I asked for and/or was offered respite care,  
(Please can you give us the details of the respite service you received)?

I. **Respite Provider Name**.....

II. **Respite quality:** very good / satisfactory / poor / unacceptable

III. **Level:** sufficient / insufficient

IV. **Funding:** Fully-funded / part-funded / not funded / other.....

- b) **If you did not get respite care** when you needed or asked for the service, can you tell us why?

I. Ineligible / cost / I refused the respite support offered / I didn't know about respite care / other.....

Please use this box if you have any further comments about your experience of respite care.

**13) Do you get regular breaks from caring? (Please tick/circle all answers that apply). YES / NO**

- a) **IF YES:** Please can you tell us about the frequency, provider and type of breaks you get?

I. daily / weekly / monthly / rarely / never.....

II. Social care / charity / family / other.....





# Appendix 7 Questionnaire: Young Carers

## Young Carers Questionnaire

We don't need your name on this questionnaire as your answers are anonymous. The information we collect from you will be used to help make Young Carers lives in North Somerset better in the future.

Town/Village I live in? .....

Name of GP/Health Centre I go to .....

Your Age .....

Male / Female (please circle)

1. Can you tell us who you care for? (please tick all answers that apply)
  - a) Parent / Elderly Relative
  - b) Child / Young Person
  - c) Other Family Member
  - d) Other.....
2. Can you tell us how long you have been a carer? (please tick one answer only)
  - a. Under a year
  - b. Between 1 and 3 years
  - c) Between 4 and 10 years
  - d) Over 10 years
3. Roughly, how many hours a day do you provide care? (please tick one answer only)
  - a. Up to 10 hours
  - b) 11+ hours
4. Have you been given information about what help you can get?
  - a. If YES Who gave you the information? .....
  - b. If NO How did you/do you find out information? .....
  - c. I DON'T KNOW what help is available .....
5. Do you get any other help to look after the person you care for?
  - a. If YES Name of organisation/person who helps you .....
  - b. If NO Do you know why not?.....
6. Would you like more help? (please circle one answer) Yes / No / Don't know
7. Does your Doctor know you are a carer? (please circle one answer) Yes / No / Don't Know
8. Does your School know you are a carer? (please circle one answer)  
Yes / No / Don't Know
9. Do you know what to do if there is a problem or if things go wrong? (please circle one answer) Yes / No
10. Have you ever needed support in a family emergency? (please circle one answer) Yes / No

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- a. If YES did you get the support Yes / No
- b. If you did get support who helped you? If you needed support in an emergency and didn't get it, do you know why?

11. Do you get regular breaks from caring Yes / No

- a. IF YES Please can you tell us about how often?.
- b. If NO Can you tell us why?

12. Do you feel you have any one to talk to about your caring responsibilities?

Yes / No

13. Would you like someone you know you can contact to talk to? Yes / No

14. What makes you the most stressed and unhappy about being a carer? Please rate on the scale of 1 to 5 - with 5 being the highest cause of stress/unhappiness (Please rate all the answers that apply)

- a. Tiredness ① ② ③ ④ ⑤
- b. Your own health ① ② ③ ④ ⑤
- c. Your own mental health ① ② ③ ④ ⑤
- d. The responsibility ① ② ③ ④ ⑤
- e. Not getting support ① ② ③ ④ ⑤
- f. Not having a break ① ② ③ ④ ⑤
- g. Not being listened to by professionals ① ② ③ ④ ⑤
- h. Not been given enough information ① ② ③ ④ ⑤
- i. Not being able to do school work ① ② ③ ④ ⑤
- j. Worrying about the person you care for when you are not home with them ① ② ③ ④ ⑤
- k. Other (please say) \_\_\_\_\_

15. Please use this space below to tell us if there is any other help and support you would like to receive that would help you in your caring role, or any other experience you would like to share about being a Young Carer

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