

Young Carers Speak Out!

Final Report

Dr. Jen Lyttleton-Smith

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CASCADe

Children's Social Care
Research and Development Centre

Canolfan Ymchwil a Datblygu
Gofal Cymdeithasol Plant

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INTRODUCTION

This report considers the opinions and experiences of children and young people identified as 'young carers' in the Cardiff and Vale of Glamorgan regions of South Wales as they relate to the main aims of the Carers Strategies (Wales) Measure 2010.

POLICY CONTEXT

The Carers Strategies (Wales) Measure 2010 issued revised guidance to Local Health Boards, NHS Trusts and Local Authorities regarding their support of and engagement with adult and young carers. Acknowledging the significant population size and value to the health and wellbeing of local communities, the legislation set out new aims for the relevant bodies in relation to their support and empowerment of carers.

Cardiff and the Vale of Glamorgan Local Councils developed five programmes of action to work with carers in their region in fulfilling these aims, and each of these relate to a section of the data reported here:

1. **Partnership working** - a partnership framework to ensure that the Health Board, Local Councils and the third sector work together to support carers
2. **Awareness raising** - an awareness raising framework, to ensure that everyone who needs to be is "carer aware"
3. **Education and training framework** - to ensure that the training needs of healthcare staff and carers are identified and met
4. **Information framework** - to ensure that all carers are provided with appropriate information at all stages of their caring pathway
5. **Carers pathway** - to identify the information and support health services can provide to people throughout their time as a carer

Young carers are identified in the legislation as a group with specific needs requiring focused attention. The survey discussed in this report was designed by the above Local Councils in consultation with an advisory board of young carers to identify these needs and to inform the ongoing 'Partners in Care' collaboration between Cardiff and the Vale of Glamorgan.

DATA SOURCES

This report features a range of data sources. The primary source is the results from an online survey designed by the Cardiff and Vale of Glamorgan Councils in consultation with young carers.

Further qualitative data was produced during the course of the 'Young Carers Speak Out' event in Cardiff on the 31st March 2016. This event was collaboratively organised by the YMCA, Cardiff and Vale University Health Board, and the Cardiff and Vale of Glamorgan Councils to provide respite and information to local young carers, and over 50 children and young people attended on the day. As part of the event, CASCADE designed and facilitated a

variety of creative data-generation workshops that would provide the opportunity for the young carers to give their opinions and relate their personal experiences.

ONLINE SURVEY

The survey data presented was generated through an online questionnaire available for completion by young carers in early 2016. The number of completed surveys totalled 101 out of a sample of 230 young carers between the ages of 7-18¹ residing in Cardiff and the Vale of Glamorgan at this time.

The survey includes a demographic 'About You' section and five further sections that directly relate to each of the five programmes of action developed by the above Local Councils.

Section 1: About you

- Includes: sex; age (banded); county of residence; educational status; and relationship to cared-for person/people

Section 2: Partnership working

- Includes: identifying supportive relationships; assessing communication between supportive individuals; ideas to improve supportive relationships

Section 3: Awareness raising

- Includes: assessing the awareness of relevant individuals; feelings about current institutional support received and how it could be improved; feelings regarding treatment by others as a young carer

Section 4: Educational framework

- Includes: assessment of current skill set; confidence levels in caring; desire for further learning/training

Section 5: Information framework

- Includes: sources of information regarding caring; quality/quantity of available information; ideas for improving information

Section 6: Carers pathway

- Includes: assessment of caring role by others; information sharing during hospital admittance; opportunities for decision-making relating to role as a young carer

Wherever possible a visual representation of the responses to each question has been provided. Depending on the form and style of the question, these visual representations may refer to a percentage of respondents, or numeric response counts, and this is indicated in each case.

¹ Two respondents were over 18 but as they had recently left the project their views were welcomed.

The survey provided many opportunities for respondents to use free text entry boxes to supply more detail concerning their responses, or to otherwise provide information. These are included throughout in the form of lists, tables, and summaries where appropriate.

Please note: where free text entry boxes were provided, many of the responses included were not substantive (that is, they gave no meaningful or appropriate information, the most typical example being 'no'). These responses are excluded for clarity and brevity, so where free text responses are reported here, only substantive content is included.

CREATIVE WORKSHOPS

Concentric Circles: Mapping relationships

In this activity, children were given charts to complete to illustrate which people they were closest to in life and who were giving them the most support both emotionally and physically, providing a map of their support networks and relationships that they would like to see improve. Figure 1 shows an example worksheet from this exercise. The three concentric circles around the figure labelled 'me' are titled: 'people closest to me', 'people I am less close to' and 'people who are around'. The 16 year old who completed it has drawn arrows to indicate relationships that they would like to be closer. For example, they would like their teachers to shift from being 'people who are around' to 'people I am less close to', showing a desire for a slightly closer relationship.

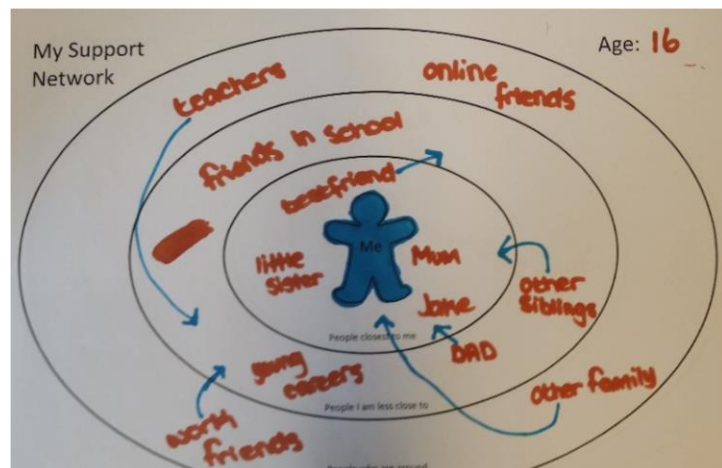


Figure 1: Concentric Circles

Timelines: When and where caring happens

For this activity we provided the young carers with daily timelines to complete in a way that would represent their typical caring responsibilities and how they fit into the rest of their lives. The children and young people were encouraged to be creative and decorative in completing their worksheets, and were provided with stickers and coloured pens to make the activity enjoyable.

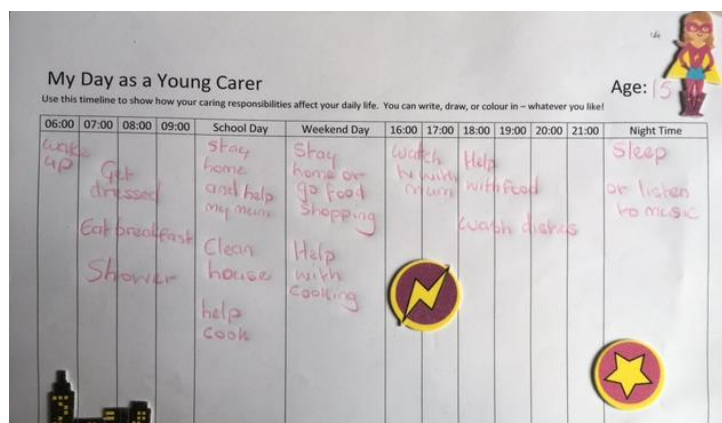


Figure 2: Timelines

Bricks: The supporting wall

This activity asked young carers to build a wall of paper bricks naming the people who supported them in their role as a young carer. This would enable us to identify the people who were exceptional at helping and understanding young carers.

Washing Line: Airing caring

This activity represented the dual nature of being a young carer, which brings both difficulties and, potentially, possibilities for closeness and happiness. A washing line, complete with pegs, was strung across the length of a large room. The young carers were provided with paper that on one side had the title, “What I most enjoy about being a young carer”, and on the other side, “What I find most challenging about being a young carer”. The young carers completed each side, often adding more than one thing, and hung their papers on the washing line, with ‘challenges’ all facing out one side, and ‘best things’ facing out the other.

Worry Rocks: A heavy load

This activity captured young carer’s fears and worries by writing them down on papers that were wrapped around rocks and deposited in a backpack. These could be related to any aspect of their lives but many were directly linked to being a young carer. Once full, the backpack of ‘worry rocks’ was heavy and unwieldy, symbolising the weight of their fears that they carried with them from day-to-day. The young carers were invited to wear the backpack, with removal a cathartic experience of ‘letting go’ through sharing.



Figure 3: Flowers

Flowers: Helping young carers grow

This activity provided groups of young carers with a large flower outline for them to cover in Post-It note ‘petals’. On the petals they were asked to write down things in their lives that made them feel good and happy, and helped them to manage the more difficult aspects of their lives.

Focus Group: Advising peers

This activity took the form of informal focus groups where children and young people were asked to discuss what advice they would give to new young carers given their own experiences. Through this we sought to capture the expertise of young carers and establish what forms of knowledge and support would be helpful to offer to new young carers.



Figure 4: Letters to the First Minister

Letters to the First Minister: A vision for the future

In this activity we wanted to provide an opportunity for young carers to communicate their ideas and desires for the future. In order to contextualise the impact that we hope their thoughts may have on future policy and practice, we created a format whereby the children and young people would anonymously complete template letters addressed to the First Minister for Wales, which were then 'posted' in a collection box styled like a Royal Mail postbox.

The letter prompted the young carers to complete three fields:

- "What change I would like to make my personal life as a young carer better"
- "What change I would like to the support that all young carers get"
- "What change I would like for society to help and understand us better"

It is intended for the messages from these letters to be delivered to the office of the First Minister in the near future.

SURVEY AND WORKSHOP FINDINGS

This section of the report presents the survey data obtained through the online survey and the creative workshops. It gives a broad overview of the experiences of young carers in Cardiff and the Vale of Glamorgan, and how they feel about the institutional and personal support and information offered to them in their caring role. It is structured in relation to the various sections of the survey, and the data presented from the survey is complemented wherever appropriate by corresponding workshop data.

SECTION 1: ABOUT YOU

The survey was successful in capturing a broadly representative range of respondents from the target population.

Figure 5 shows the balance of respondent sex identification.

- 49 respondents identified as male
- 50 respondents identified as female
- 2 respondents selected the option 'other', one describing their identification as 'non binary' and one as 'gender fluid'

Figure 5: Sex Identification

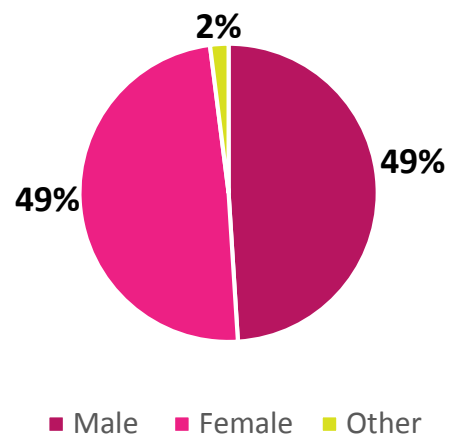


Figure 6 shows the number of respondents identifying within four age bands. There are: 31 aged 7-10; 32 aged 11-13; 36 aged 14-17; and 2 aged 18+.

Figure 6: Age Band

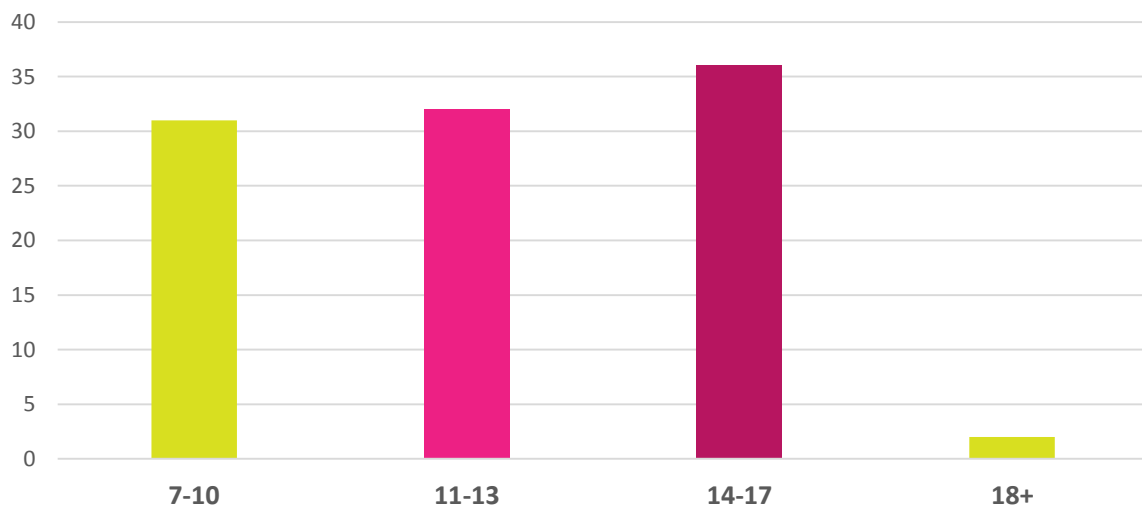


Figure 7: Location

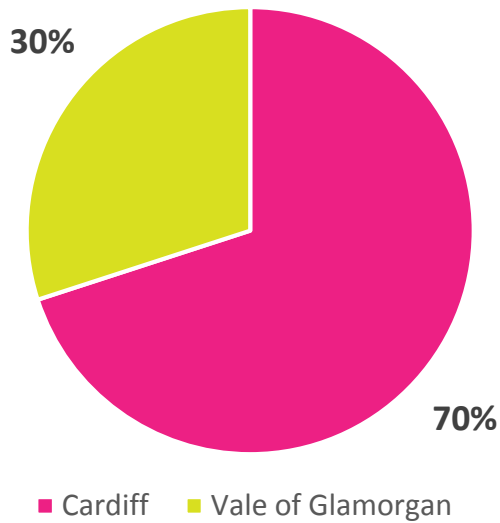


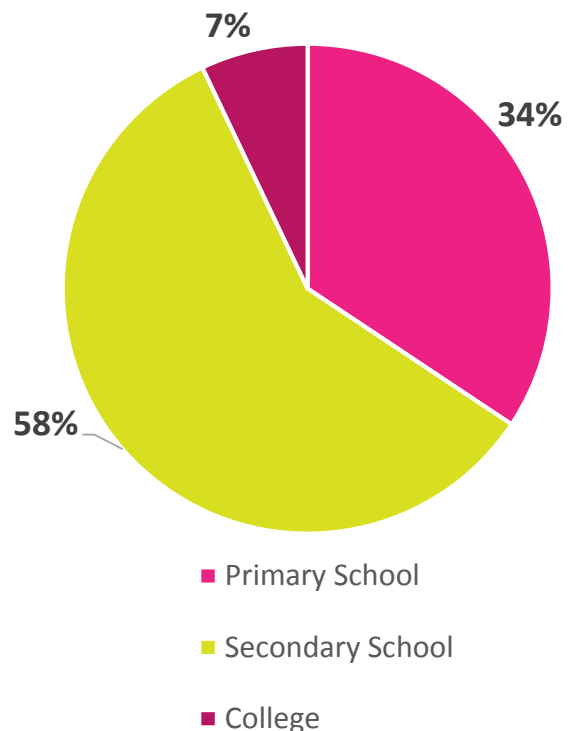
Figure 7 shows the balance of survey respondents from each Local Council area: 71 reside in Cardiff and 30 in the Vale of Glamorgan.

Figure 8 shows the current educational institution attended by respondents. 33 respondents report attending primary school. 56 report attending secondary school, and 7 are in college.

Five respondents did not identify themselves as being in education.

- Three are aged 14-17. One stated that they are in part-time employment; one is training with ACT; one is being tutored out of school.
- One is aged 18+ and stated that they have no employment
- One was aged 11-13 and therefore it may be assumed that this was an unintended omission²

Figure 8: Current Education



² The survey also asked "If you are not in education, what are you doing now?" and provided a free text entry box for respondents. Though there are thirteen responses to this question, none report any substantive information apart from the aforementioned 14-17 year old who relates their part-time employment and notes that they are "working towards a promotion".

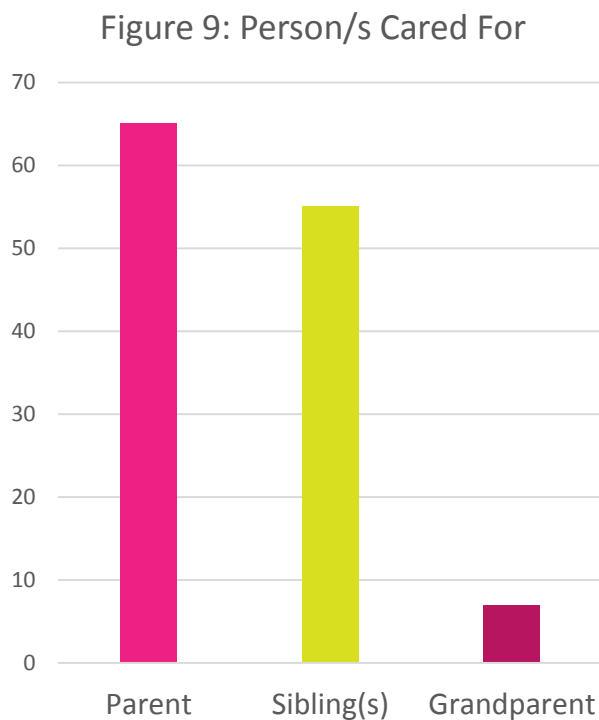


Figure 9 shows which relations the respondents reported being responsible for as a young carer. This question permitted multiple entries and therefore absolute numbers are included here, rather than percentages.

66 respondents report caring for parents; 56 for sibling(s); and 7 for a grandparent.

Of the 26 respondents who identified more than one caring relationship, the most common combination reported by 25 respondents was a responsibility for a parent and sibling(s). Three of these respondents also reported caring for a grandparent, while one further respondent identified only a parent and grandparent.

SECTION 2: PARTNERSHIP WORKING

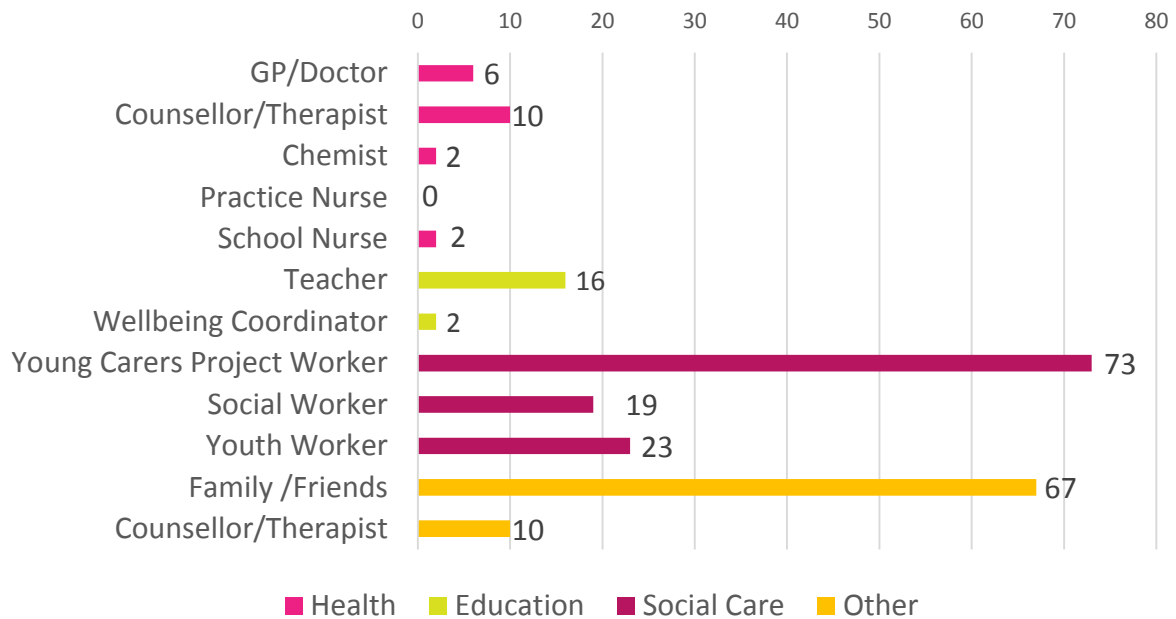
Support Networks: Survey data

The survey respondents were asked to identify who 'works with' or 'supports' them as a young carer, with multiple choices permitted. Eleven different possibilities were suggested, as well as an 'other' option, with free text entry for respondents to supply further detail.

Figure 10 shows the number of responses for each of the suggested people. The suggestions are categorised into four broad categories for analytic purposes: health; education; social care; and other. This data illustrates the critical role that social care professionals and family/friends play in supporting young carers, whilst highlighting the minimal input of medical and nursing professionals.

Eight free text entries for respondents to state other sources of support produced a variety of responses including: 'School Counsellor (F.A.C.T)'; 'Child minder'; 'Brother'; 'Mentor'; 'Nature'; and 'Myself'. Two respondents here simply stated 'No one'.

Figure 10: Who works with or supports young carers?



Support and Communication

Figure 11 shows respondent views regarding the level of communication between the people who work with them. The question asked, “Do you feel the people who work with you talk to each other to make things as good as they can be for you?”

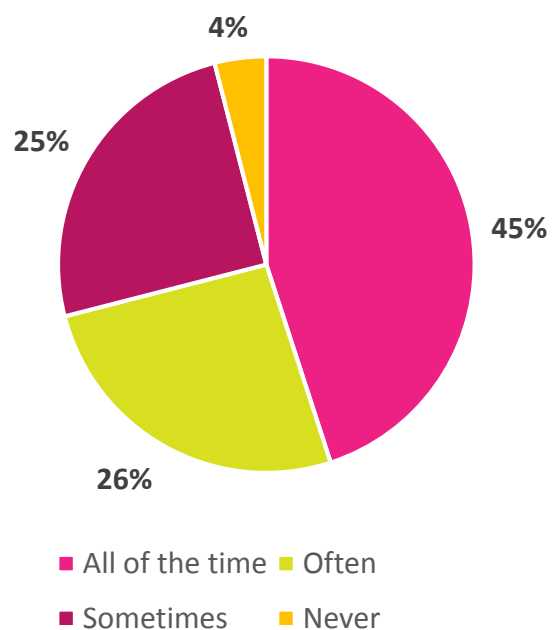
Respondents were prompted to supply more detail here in a free text box and many (25 in total) chose to do so.

Several express frustration that communication was poor or non-existent, or that while their support network communicates with each other they do not sufficiently communicate with them as a young carer:

“No one communicates, one says one thing the other another”

One respondent notes discussions with other young carers as a source of support, while others made general comments about adequate communication. Some comments are less relevant: one praises Young Carers Project workers for trying to ‘make things fun all the time’, and another for making it possible for them to get out of the house.

Figure 11: Communication



One comment is particularly detailed and insightful as to experiences relating to communication and support:

“School not always aware of my issues and are not always kind if I am late or cannot do my homework. Social workers just judge us and don't help. counsellor not always there and does not know about caring and how it hurts and makes me sad and angry my young carers worker is fab and is always there and helps with school and social worker and my family and knows everything about what is going on and I don't have to explain if I don't want to”

Improving Support

Respondents were asked to share their ideas for how their support could be improved in a free text box. All responses with substantive content are reproduced here.

- A nurse for my dad
- Communicate better
- Get them to help me a bit more with my education such as basic life skills
- Go to my school
- GPs can do more to help
- I think they need to be supported as well to function as a support group to young carers like me. And in my experienced they are doing well
- I'd like someone to talk to, to help me cope with things
- If people were aware what really goes on and what a young carer does at home. Allow them to see how stressful it can be
- If someone could help me
- Information about the situation could be shared
- Money
- More efficient
- More fun activities
- More help
- No. Please take me to Florida. More money for trips.
- Not really they are legit
- School and teachers helping me or talking to me
- School support
- Social workers acting on serious things.
- Somebody to talk to in school
- Someone in school I can go to as soon as I have problems that will be the same person and will explain to other staff so I don't have to in front of other pupils. Different people asking me the same questions, why cannot people share my information so I don't have to repeat myself? Keep the same social worker I am sick of the constant change, some are fab others are really bad and nasty to us. More chances to see my counsellor would not change project or carers worker other than to see them more and more trips and outings would be nice so I can relax and see my friends and Julie.

- Something more personal to talk about stressful situations.
- Support for adults
- Take me out more
- They need to work together as one group
- Work more closely with carers and ask how they're feeling
- Young Carers project help me.

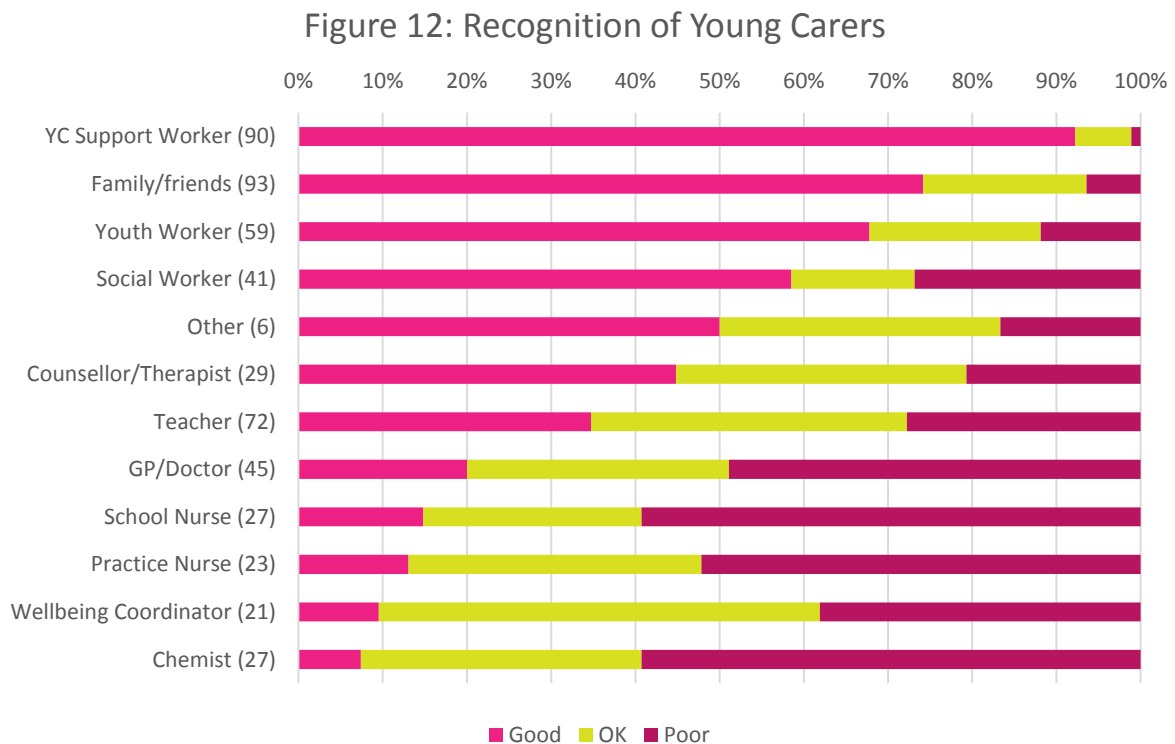
SECTION 3: AWARENESS RAISING

Recognition of Young Carers

The first question in this section asked respondents to rate a number of professionals (and family/friends) with whom they may have contact based on recognition of their role as a young carer. The options provided were:

- Good
- OK
- Poor
- Don't know

Figure 12 illustrates the balance of ratings for each person/people. For the purposes of representation, and given that many of these answers would have been provided due to a lack of any contact, 'don't know' answers have been omitted in every case. Therefore Figure 12 only represents responses where a clear opinion is provided. The numbers represented vary in each case and are provided next to the category titles on the left.



These findings map closely onto the data represented in Figure 10 above, which referred to the individuals offering support to young carers. Unsurprisingly, those who are the most common sources of support are also those who are best at recognising the role of young carers.

The individuals who score highly on their recognition of Young carers are those who are specifically concerned with their care and overall wellbeing (for example, family and social workers). Where the roles of professionals are more narrowly defined or less directly concerned with matters of wellbeing (for example, chemists and teachers) their reported recognition is lower.

The next question on the survey asked respondents, *“Can you tell us why you think they are good/ ok/ poor at recognising you as a young carer?”* This was a free text entry field and 51 respondents answered.

The most common issue raised in response to this question is that of communicating the responsibilities of the young carer to the adults listed, particularly teachers. Some appear confused or uncertain regarding whether their teachers are supposed to know about their situation, and if so, who should tell them about it.

Positive experiences are reported when people take the time to ask questions and listen:

“Teachers take me out of class and talk to me about my dad and ask how he is doing”

“My family/friends and the young carers (Project Workers) are good at recognising me [and] I go on the trips”

“Because [Young Carers Project workers] are fun and they are knowledgeable and listen”

Some have more negative experiences to report:

“Chemist asked me when getting sleep pills, teachers don't really care, friends don't ask that much”

“My teacher does not ask at all but she knows that I have struggles at home”

“Because my mum's illness is theoretically invisible” (Having rated every individual named as ‘poor’)

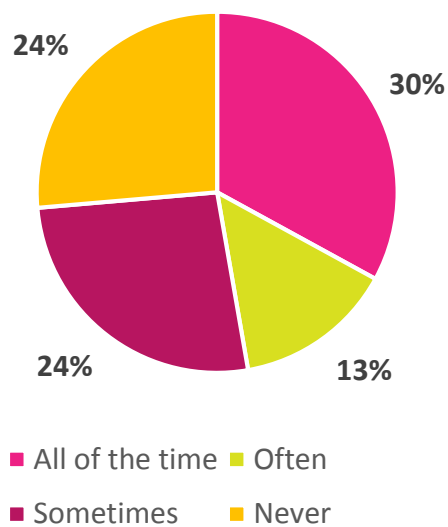
One respondent in particular is broadly disillusioned regarding how others perceive them as a young carer and summarises many of the key challenges facing this group in their daily lives. However, they also highlight some important points of acceptance and understanding:

“My inclusion officer at school is cool but pupil support always too busy. My doctor treats me like a child and will not listen. Chemist is nice when I pick up medication. Social workers okay but just as I trust them they leave and we have to start again!!!! Teachers are pants they just want to shout and not listen. Counsellor cool, I can relax for a little while and be listened to ... Project worker listens, is there for me, makes me smile and understands and being on the project makes me feel like I belong and I don't have to explain anything as we just relax and are all the same. Some friends are cool but some take the mick or complain when I cannot come out. Family are only there when it

suits them or they want to look good. People in school make fun of me because I am late and cannot go out with them in the evenings as I have to go home and always ask too many questions”

The Right Support?

Figure 13: Do they give you the right support?



The next question in this section relates specifically to the level of support offered by education and employers, asking, “Do you feel that you have the right support from your school / college / employer as a young carer?” In Figure 13 the four possible answers have been reduced to two for simplicity of representation, and largely represent schools and colleges, as only three respondents did not report school/college attendance.

The responses here illustrate how the support offered by educational institutions for young carers is simply not meeting their perceived needs the majority of the time, with only 43% feeling that they were always or often given the right support.

This question also included a free text entry box for respondents to give more detail relating to their experiences of support. While there are 29 free text entries here, only 22 respondents chose to give substantive detail, and the vast majority of these (17) come from those who responded ‘sometimes’ or ‘never’ receiving ‘the right support’, indicating that they relate to overall negative experiences. These responses are reproduced here:

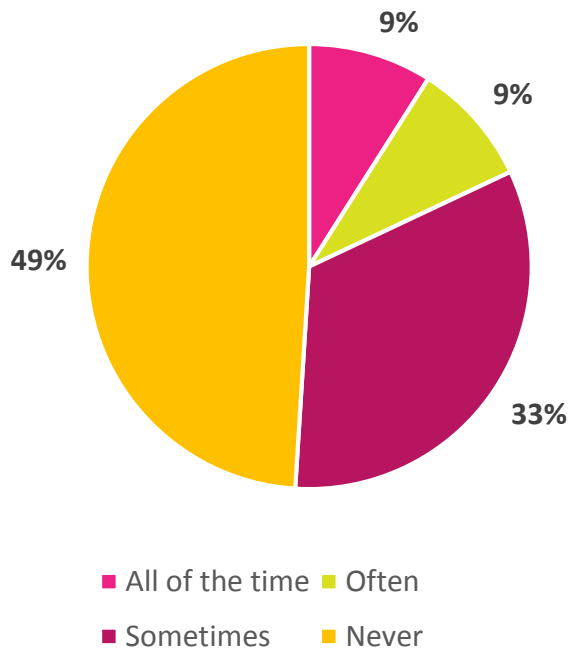
Table 1: Detail about support

Response: Do you feel that you have the right support from your school?	Response: Please tell us a bit more about this. (Optional)
All of the time	<i>Always when I need them</i>
All of the time	<i>Extra support</i>
All of the time	<i>Pastoral, pupil support.</i>
Often	<i>My school knows that I</i>
Often	<i>They provided me with a counsellor and they also provide me with any ingredients that I need for cooking.</i>
Sometimes	<i>I was made to go and calm my brother down.</i>
Sometimes	<i>[One teacher] is great, pupil support is bad, some teachers are okay but even the ones who know are really rude and shout and don't let me explain stuff even though they know I</i>

	<i>have to care then I get angry and get into trouble because they don't show me respect. It would be nice to have time out, there are lots of young carers in my school who attend the project and sometimes it would be nice to have time in school with them and if we got together we could all maybe talk to the school together about what we want and need and what the school can do.</i>
Sometimes	<i>Sometimes I get more time for homework but not all teachers do this</i>
Sometimes	<i>Sometimes the wellbeing department staff in my school speak to me and let me know everything is ok or I am allowed to speak to them if I would like to.</i>
Sometimes	<i>They don't always listen</i>
Sometimes	<i>They don't listen very often.</i>
Sometimes	<i>They don't really recognise it all that often</i>
Sometimes	<i>They make my life more difficult and stressful. Won't let me do what I need/ want to do.</i>
Sometimes	<i>Understand homework not done</i>
Never	<i>A few of the teachers know but I don't have any help</i>
Never	<i>I need someone to talk to in school</i>
Never	<i>I want more support</i>
Never	<i>I'm not recognised as a carer and they don't know about my brother.</i>
Never	<i>Never - school</i>
Never	<i>The school doesn't care</i>
Never	<i>They don't know I'm a young carer or don't ask me</i>
Never	<i>They don't talk to me about it</i>
Never	<i>They talk to my mum but not to me</i>

Treatment by Others

Figure 14: Do you feel you are treated differently?



The next question is somewhat problematic for analysis in that it has two different possible interpretations. The survey asked, “Do you feel you are treated differently because of your carers role?” and the responses are shown in Figure 14.

Some young carers might see being treated differently as a positive thing, with their particular issues and concerns being accounted for and accommodated by others (for example, having more time available to submit homework assignments). However the question could also be interpreted as relating to negative experiences of not receiving equal treatment to others, therefore caution is advised in interpreting these responses.

This question included a free text entry box for respondents to supply more detail if they chose, and the ambiguity of the question is visible in these responses. There are 18 in total, with 12 of these offering substantive detail. These 12 have been reproduced below alongside the multiple choice selection of each respondent, illustrating how the question has been interpreted in the different ways described above.

Table 2: Being treated differently

Response	Detail
Never	<i>I feel treated the same because they don't say "do you need help?" all the time.</i>
Never	<i>Because it doesn't affect me</i>
Often	<i>Because I can't go shopping with friends</i>
Never	<i>everyone is different but no one treats me differently</i>
Sometimes	<i>because I have to have a social worker and I get to go on the project but that is good most of the time but sometimes people look at me down their noses as if there is something wrong with me and my family and we are just normal but need help sometimes to make us happy.</i>
Sometimes	<i>People treat me like I'm a lot older than I am.</i>
Sometimes	<i>Sometimes because we will get more attention which I personally enjoy/like</i>

Sometimes	<i>Yes my worker in school will ask for me to see her outrightly during lessons and peers will ask questions.</i>
Often	<i>Often you get too much sympathy but no support</i>
Often	<i>My GP asks me questions</i>
All of the time	<i>They are aware of my brother's disability and they are very helpful and supportive of us.</i>
Sometimes	<i>Sometimes in school</i>

SECTION 4: EDUCATIONAL FRAMEWORK

Caring Skills

The first question in this section asked, “Do you feel that you have the skills needed to carry out your role as a carer?”

The responses are illustrated in Figure 15, and show that young carers generally feel appropriately skilled in their caring roles, with over two thirds reporting ‘always’ or ‘often’.

This question offered a free text entry box for detail to be added. Most respondents who contribute extra detail refer to practical matters such as shopping or cooking. However some respondents express concern about their ability to offer emotional support, with one expressing confidence in this regard while others refer to anxiety or confusion about this particular issue.

Figure 15: Do you feel you have the skills needed to care?

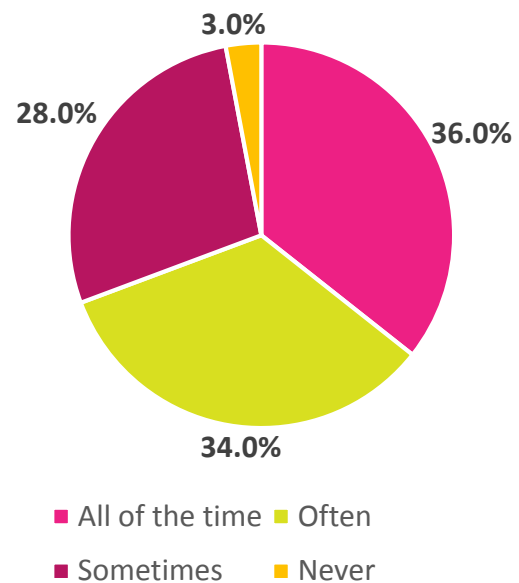
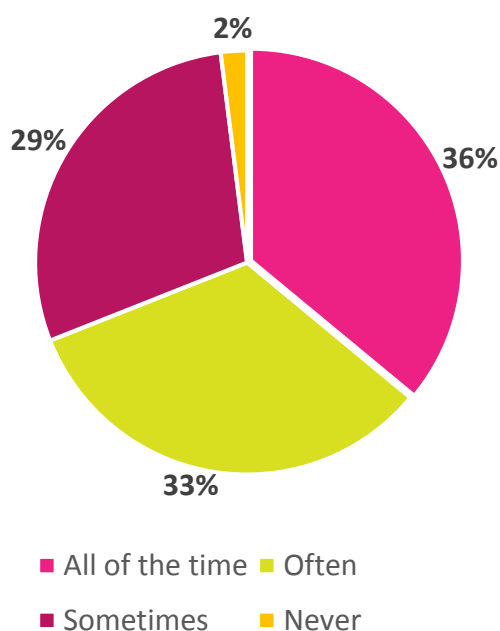


Figure 16: Confidence in caring



Confidence in Caring

The next question asked, “Do you feel that you have the confidence to carry out your role as a carer?”

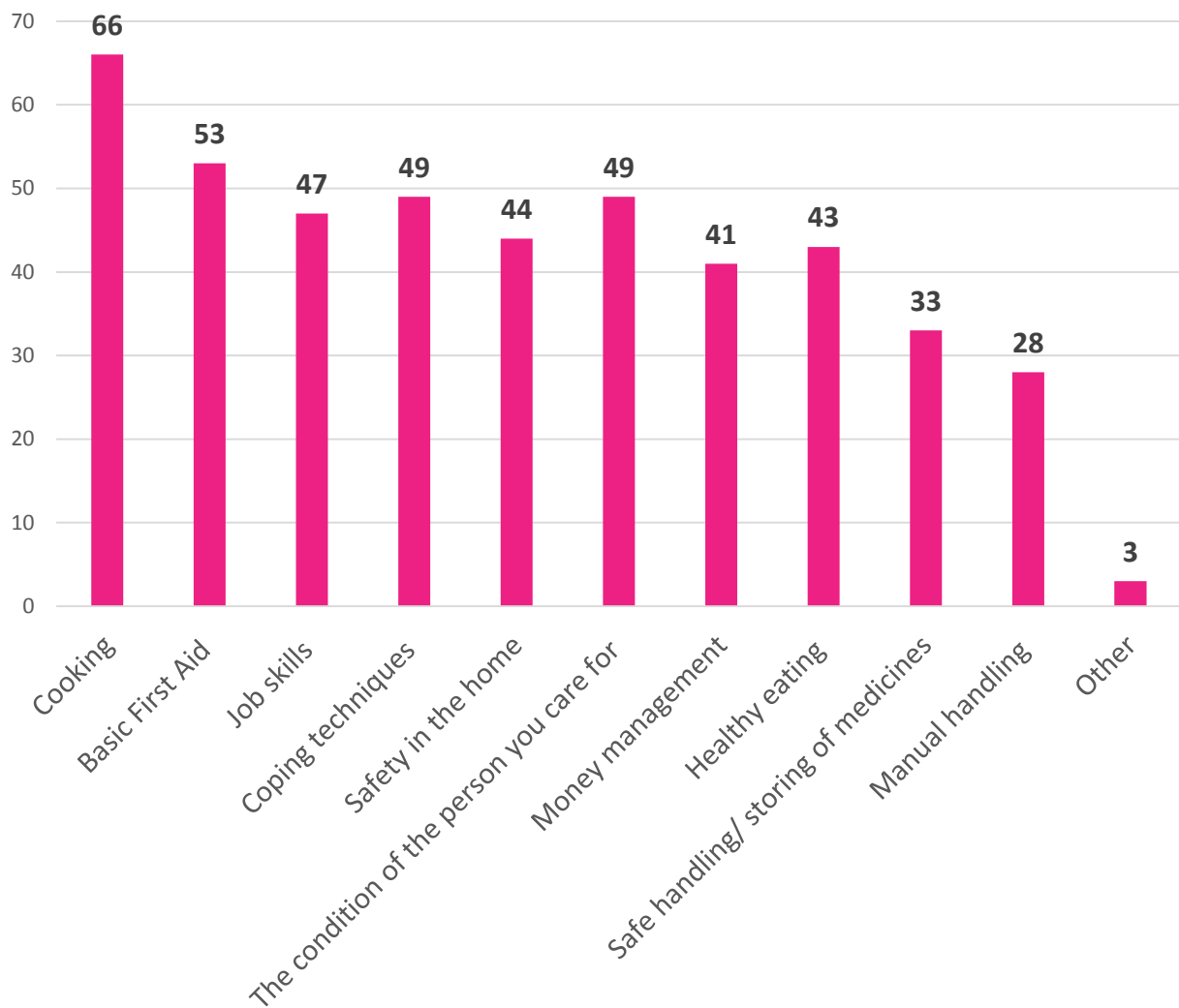
These responses are illustrated in Figure 16, and show young carers reporting a high level of confidence in caring, with over two thirds responding ‘always’ or ‘often’.

This question offered a free text entry box for detail to be added. Although 18 respondents chose to enter a response here, there was very little of substantive interest, with most simply stating that they did or did not feel confident (corresponding to their multiple choice response). Two respondents

reported feeling anxious or scared sometimes but did not give further detail here.

Respondents were asked to choose from a list of topics that they would like to learn more about. As Figure 17 shows, there was broad interest in all of the listed topics, with cooking being the most popular. With regards to medicines and manual handling, these topics would only apply to certain Young carers, which may explain the slightly lower levels of interest here. The two respondents who selected 'other' expressed an interest in learning more about sports and 'fitness for the person you care for'.

Figure 17: What young carers want to learn more about

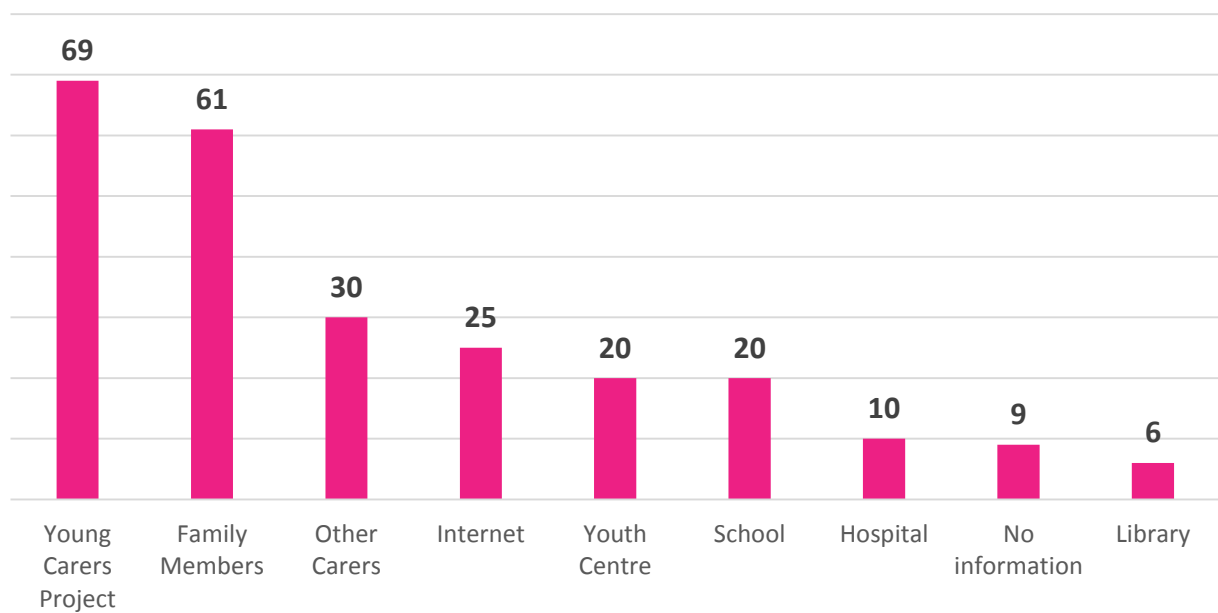


SECTION 5: INFORMATION FRAMEWORK

Where Young Carers Get Information

Figure 18 shows responses to the question, “Where do you currently get information to help you in your role as a carer?” Multiple choices were permitted, with 13 options to choose from, but several were selected by only a few respondents and are therefore omitted from Figure 14 for brevity. These include: ‘Health Centre’ (2); ‘Local Council’ (2); ‘Other’ (2 – no detail given). ‘Chemist’ was also included but no respondents selected this option.

Figure 18: Where young carers get information



The next question asked where respondents would *like* to get information from, with a free text entry box provided. Of the 48 responses here, 21 include substantive detail. Desired sources of information include:

- School (8)
- The internet/websites (5)
- Hospitals/chemists/doctors (5)
- Family members (2)

Other responses include:

- Emails to me
- Young carers
- Books
- Youth centre
- From YC project worker
- YMCA

Notably, two respondents in the 7-10 age band report difficulty in accessing appropriate information for their age. One says that they are 'too young' to get information from people, while another says that they would like 'someone to help me understand'. This would suggest a need for more accessible information tailored to this younger age group.

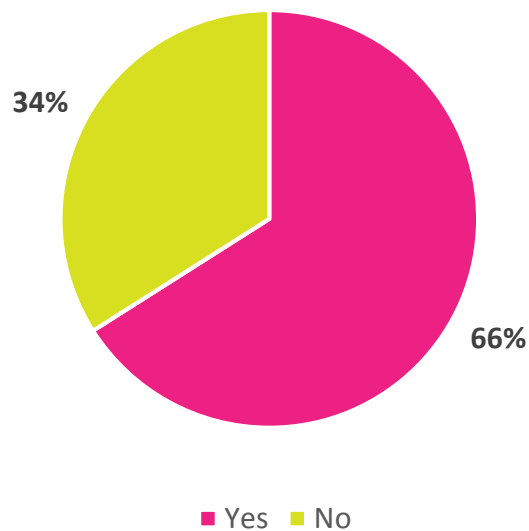
Quality of Information

Figure 19 shows the balance of responses to the question, "Do you think there is enough information available to you as a carer, and is it up to date?"

While the majority of respondents are satisfied with the quality and timeliness of the information available, some concerns are expressed in free text entry. Responses with substantive detail are included below. These responses are disparate and cannot be summarised easily, though it is notable that one younger respondent refers again to a lack of age-appropriate information, while another is clearly disappointed with the lack of information provided by their social worker.

- Young Carers project
- Not another places. There's only the internet.
- I can just ask.
- I know the basics to look after my mum as well as the house.
- Other than from [YC project worker] I have never had any information and nor have my family. My social workers don't know anything and have never helped us with caring or helped me feel happy
- Not sure how to access info
- I don't get told everything.
- Even if there is it is hard to find
- I'm too young
- My mummy and daddy let me know any information

Figure 19: Is enough information available and is it up to date?



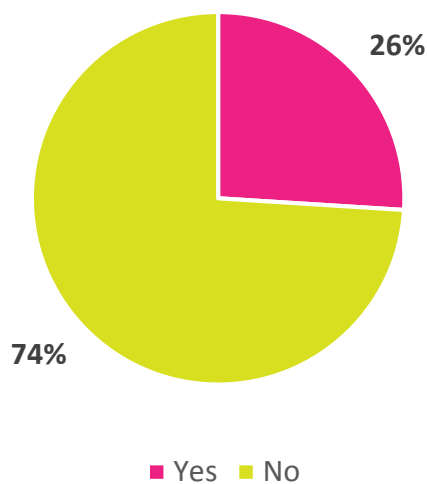
Improving Information

To conclude this section of the survey, respondents were asked to provide suggestions for how information for young carers could be improved. Of 41 responses here, 15 had substantive suggestions and these are listed below. Five of these refer to the internet, email, and social media as desired channels for information, while several others are more concerned with the depth or quality of the information itself.

- More young carer workers
- Put it on a social site
- It could be improved via the social media
- Posting letters
- More educational
- Have sessions in school explaining what a young carer is and what we do and feel have more project workers so more people can get help have a site we can find on the internet about caring
- Posters, awareness events leaflets
- It could be more in-depth.
- Explaining the idea more
- Update 24/7 by email or text
- Clubs, emails.
- Keeping me up to date.
- Better explained
- It needs to be set out in a more child friendly way
- In school

SECTION 6: CARERS PATHWAY

Figure 20: Have you ever been assessed by someone as a young carer?



In the final section of the survey, questions relate to the early identification of young carers and their involvement with decision making. Figure 20 shows responses to the question, “*Have you ever been assessed by someone other than a Young Carers project worker about your caring role?*”

Of the 19 ‘Yes’ responses, six gave substantive detail regarding who had assessed them:

- FACT
- Social services
- Counsellor
- CAHMS
- School
- Social worker

Information Sources on Hospital Admittance

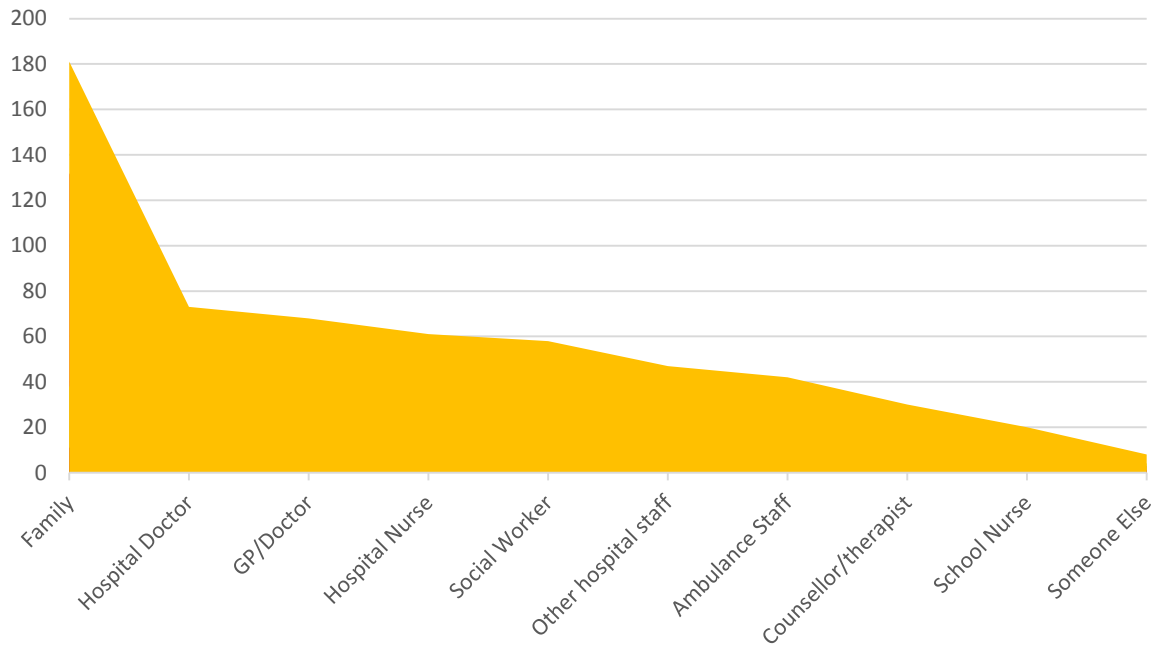
The next question asked, “*If the person you care for has ever been admitted to hospital, how much information were you given by the following people?*” and listed ten possible people/groups who might have spoken to a young carers about this event. In each case, respondents were asked to indicate one of four possible levels of information, ranging from ‘a lot’ to ‘no information’.

The matrix of possible responses this produced resulted in a complex dataset that is challenging to represent visually in its entirety. Therefore, in the case of each possible information source, the level of information gained has been weighted to produce a collated numeric representation of who provided the most information to respondents overall. Points for each response were allocated as follow:

- A lot of information – 3 points
- Enough information – 2 points
- Little information – 1 point
- No information – 0 points

This weighting produced a proportional hierarchy of information sources, represented in Figure 21 on the following page. This weighting shows that family members are by far the most common and extensive source of information in relation to hospital admittance, followed by a range of medical staff with whom young carers might come into contact during and after the event.

Figure 21: Sources of information on hospital admittance (weighted)



Respondents were then asked to give further detail on information sharing during hospital admittance. Most of the substantive responses here list a variety of family members who gave information. Other responses are as follows:

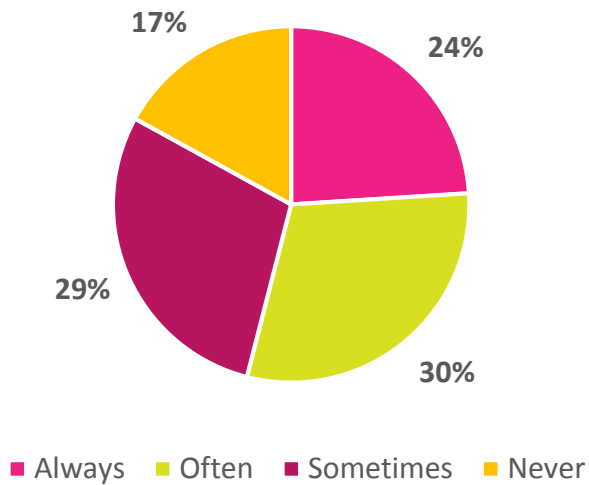
- Mostly my counsellor
- Julie explained what was happening and contacted the school, my social worker and my family to ask questions about what was happening and would happen and then explained to me.
- No one wants to tell you because your too young like we can't handle it,
- Not been in hospital much
- Because I'm the youngest I only get information from my parent

Involvement in Decision Making

The final question of the survey asks respondents, *“Do you feel you are involved in making decisions about your role as a carer?”*

Figure 22 shows that responses to this question were fairly evenly distributed, with roughly half of respondents indicating ‘always’ or ‘often’, and half ‘sometimes’ or ‘never’. This seems to illustrate the wide range of personal experiences young carers report throughout the survey, with some feeling capable and empowered, and others alienated from their peers and institutions.

Figure 22: I am involved in making decisions



Respondents were invited to give further detail if they wished and the substantive responses are included in the table below, alongside the multiple choice answer selected in each case.

Table 3: Involvement in decisions

Response	Detail
Always	Because I need help when I need to
Sometimes	I worry a lot
Never	I don't get to make decisions
Always	Well I have help but I can make my own decisions
Sometimes	Just decisions at home
Sometimes	Mum chooses what I do.
Sometimes	Other people direct my life, I just live it
Often	I can choose the activities
Never	Social worker decides everything!!! Never really acts on anything I want or ask.
Never	They never let me tell them what I want.
Often	Mum tells me a lot and I get to decide things with her.

SECTION 7: EDUCATION, SCHOOL, AND TEACHERS

Supporting Young Carers: Expectations and hopes for the future

This section explores the workshop data relating to education, schools, and teachers. The survey suggests that social and academic support in education is a key area of concern for young carers, with levels of understanding and awareness rated poorly. The workshop data relating to this topic supports and personalises the survey findings.

Key Findings from the Survey

Awareness at school

- Only 35% of young carers felt that their teachers were 'good' at recognising their responsibilities

Support at school

- 57% of young carers reported that they were never or only sometimes given the right support at school

Information

- Only 20% of young carers said that they could access information about being a young carer through school

Key Findings from the Workshops

In the **Focus Groups** many young carers noted the significant challenges that caring brought to their school life and education. Many explained that they felt teachers and schools had unrealistic expectations of what they could achieve given their personal situations due to a lack of understanding and awareness.

One group of young carers discussed their shared experiences of missing homework deadlines and their disappointment at how teachers reacted to this:

YC1: Meeting deadlines for homework assignments is the most challenging thing - schools don't really understand what a young carer does. They don't give you extra time

YC2: They don't give you the chance to explain yourself

YC3: I tried to tell a teacher one time that I had been too busy and they said it was not their problem...

YC2: They're like, "No, you haven't done the work and that's it"

YC1: There's not much awareness

YC3: They don't understand that you can't do ALL the work

YC1: You need workshops or assemblies to tell pupils and teachers what life is like for young carers and if they're aware of it then they might understand it... and you get punished, like if you get detention then it's yet another thing to deal with... it makes you feel like you've done something wrong

It can be hard for people like teachers who have had no experience of caring or any form of training on the subject to know what reasonable expectations for young carers might be, or to gain a sense of what their everyday life is like. Another group shared detailed experiences of how their school days differed to those of their peers and it would be valuable for teaching staff to be aware of these experiences:

YC1: Schools don't help, doctors... no-one. No-one recognises young carers as they are

YC2: I've got important exams coming up and I'm so far behind on coursework, and I try and explain it to them but they just see it as an excuse and say I should be able to balance it, but I really can't

YC3: A typical person now, based on when I was in high school, the kids would wake up at half 7, 8 o'clock every morning, go to school, get home and do whatever they want, go to bed at 10 or 11, whenever they want to with nothing else to do. My day, I usually wake up at 6 in the morning, you do whatever you need to do in the house first. So I wake up, do a few dishes, make my mum's breakfast, go to work for a good 6, 7 hours out the house and by the time I get back home I've got to help my mum around the house, cleaning the house and then I'm not in bed till about 12 o'clock, and then it just repeats over and over again... schools need to relax the rules more for pupils like me

YC2: I'm redoing a year of school, I failed a year because I had to take a lot of time off school because my mum and dad were in and out of hospital and not many of my family members get involved. It was just left to me to look after my siblings, look after my family. My day's a lot different to [YC3] cos I wake up at 4 in the morning, I have to get my mum and dad downstairs which takes a lot because they're heavy. I then have to bathe my younger sister. I then have to get my other two siblings up for school. I then have to make breakfast for everyone. I then have to make sure that the carer who looks after them while I'm at school comes on time cos I can't leave for school unless the carer is there. And I don't know what goes on when I'm not there so that's why I'm constantly texting my mum to make sure that everything's ok. Cos you hear stuff on the news - carers lashing out

The concerns expressed in the above conversations link closely to the data produced in the **Letterbox** workshop. When writing about their hopes for future changes and developments, 50% of the young carers' letters (22 of 44) identified a desire for more support from schools/education/teachers. 20 of these comments discussed a need for more support,

understanding, and awareness from teachers and schools regarding young carers in their care. Representative comments include:

“Workshops that go to schools to make teachers more aware of the difficult position and that we can't always meet deadlines”

“School. The teachers could help the children learn more about young carers”

“Tell our teachers so they can be more considerate on how stressful and how it takes time”

Other comments not directly linked to teacher/school awareness include:

“Help with education”

“I would like to improve the quality and availability of full time care in the form of carers so that I may focus on my education”

“Being home schooled so I can keep an eye on my mum”

The data produced through the **Supporting Wall** activity, where young carers named the people who gave them the most support as young carers, also indicated that teachers and schools are not presently playing a key supporting role in most young carer's lives. Educational institutions and teachers were identified on seven bricks out of 109 in total.

In the **Concentric Circles** activity the young carers were asked to map out their supportive relationships to explore who they felt close to and who they were less close to. No workshops participants named a teacher or teachers as one of their closest relationships, however they were frequently referenced as moderately close or distant people in their lives.

- 30% of participants (8 of 23) under the age of 13 indicated moderate closeness with a teacher compared to 10% of participants (2 of 19) over the age of 13, indicating that young children are significantly more likely to see a teacher as a supportive relationship.
- The children under 13 who listed teachers as people to whom they were moderately close tended to have smaller networks of people named as being their closest relationships. In other words, their non-educational support networks were slightly smaller, with an average of 4.75 names compared to 5.5 names of children who did not feel at all close with their teachers.

These findings suggest that the youngest and least socially supported children – arguably the most vulnerable young carer group – are those who rely the most on teachers to understand and support them in their situation. It is not possible to determine from this data whether older children do not feel a need for teachers as a source of support, or whether they have simply learnt that teachers cannot or will not offer it, hence have stopped hoping for/expecting it.

In the **Worry Rocks** workshop, where the young carers shared their biggest worries and fears relating to their role, school emerged fairly frequently in the data. Ten of 66 collected worries and fears specifically identified educational contexts and demands as their greatest source of anxiety.

A further seven comments related to bullying, a lack of understanding from peers, and feelings of isolation which could be tangentially linked to schooling contexts. As school is a common location for peer bullying, it is extremely important that schools are aware of how vulnerable and isolated young carers can feel in the school community. This is covered in 'Section 8: Friends, Peers, and Social Isolation'.

Worry Rocks: School, teachers and education



In the **Washing Line** activity, where young carers were asked to write down the biggest challenges of being a young carer, many of the children and young people expressed the difficulties of fitting in school and homework when their lives were so incredibly busy. Related to this, many said that the main challenge they faced was the amount of different tasks they had to juggle and how little spare time they had compared to their peers. Typical comments include:

"Meeting deadlines"

"Behind on school work"

"Too much work with school"

"Being tired but still having 2000 things to do"

"Hardly ever having spare time"

"I have to get my siblings ready for school or the next day as well as myself"

Washing Line Activity: The Biggest Challenges of Being a Young Carer

Conclusion and Recommendations

It is clear from the data generated through the survey and workshops that in most cases teachers and schools are not a key source of support for young carers, but many of those involved in producing this data, particularly younger children, desired better relationships and more support within educational contexts.

These findings corroborate UK-wide research by the Carer's Trust (2010), where 39% of young carers surveyed said that their teachers did not know about their caring role and, of those who reported that they were aware, 52% reported no extra school support.

It is clear in the present educational context that asking time-pressured teachers to become *ad hoc* social workers is unfeasible and undesirable in a professional and personal sense, regardless of how much certain young carers (and perhaps some teachers) may wish for this relationship. However many young carers appeared mainly concerned with an increased awareness and understanding of their situations, and this is realistically achievable through existing training and development pathways.

According to the Association of Teachers and Lecturers (2015), this is not currently being achieved, with 90% of teaching staff surveyed reporting that they had received no training on supporting young carers, and 61% reporting that this is something they would be interested in. Of the 10% who had received training, only 3% felt that training was adequate to their needs.

Based on the survey and workshop data, as well as the complementary findings by the Carer's Trust and the Association of Teachers and Lecturers, this report makes three key recommendations to implement young carers' views in policy and practice:

1. Introduce formal - ideally compulsory - training on awareness and support for young carers in education, delivered to teaching staff in schools and colleges. Primary education training may need to have an increased focus on pastoral care given that younger children are more reliant on teacher relationships.
2. Ensure that all schools and colleges have clear guidelines on how young carers should be supported in education.
 - a. *These will include pathways of support relating to homework, crisis situations, absences, phone calls home, the permission to use/carry mobile phones and send texts, and pupil engagement activities to increase awareness and understanding in the broader school community.*
 - b. *For the benefit of all parties it is likely that guidelines will need to account for the diverse situations of young carers – an individual assessment of needs that is regularly revised/updated may be the most desirable manner of tailoring guidelines to suit each situation.*
3. Compulsory education is a key channel through which information and resources could be distributed to young carers, however only 20% reported being able to access such information through school. Making sure that all schools have resource packs relating to young carers would not only assist them in finding the help that they need, but would also make them feel more supported and recognised in school.

SECTION 8: BULLYING, LONELINESS AND EMOTIONAL CHALLENGES

Feeling Different: The social and emotional difficulties of caring

This section explores the workshop data relating to the social and emotional problems that young carers face as a group vulnerable to isolation and alienation from their peers. Though there was little in the survey that addressed these issues specifically, these difficulties were consistently expressed in the workshop data. Due to the potential risks to mental health these feelings of loneliness and isolation can cause, particular when added to the extreme pressures that some young carers are under, it is critical that addressing these concerns be foregrounded in all policy and practice relating to this group.

Key Findings from the Survey

Control and decision making

- Only 54% of young carers felt that they had some influence on decision making relating to their role

Mental health support

- 21% of young carers reported having contact with a wellbeing coordinator, and 29% reported contact with a counsellor or therapist

Key Findings from the Workshops

In the **Focus Groups** many young carers referenced a lack of understanding or awareness from peers as being a significant frustration in their lives. One young carer discussed how friends might think that they understand the pressures that are under, but can't grasp the relentlessness or risks of their role:

Most people don't understand, like, if all you've been doing for the weekend is literally just being there, like my sister you have to, like, watch her. You turn your back and the entire sofa is covered in felt tip markers. People think, "Oh, yeah, my sister, she'll do that", like, "Don't worry, I need to watch my sister". You're like, "Yeah, but it's not the same thing", and they're like, "Yeah, yeah, but it is the same thing", and I'll be like, "No, because my sister will really hurt herself if I leave her alone". And they're like, "Yeah, my sister, she could drown in the bath" and I'm like, "No, it's not the same. I didn't have time to do my homework because I was actually literally looking after my sister". People are like, "Yeah it's nice to look after your family" and I'm like, they don't even... And people are, like, "Oh yeah, I do the dishes for my Nan every so often" and you're like, "It's not the same as cooking and cleaning and bringing them medication"

Other young carers discussed how this lack of comprehension and generally increased stress levels led to them being particularly vulnerable to bullying:

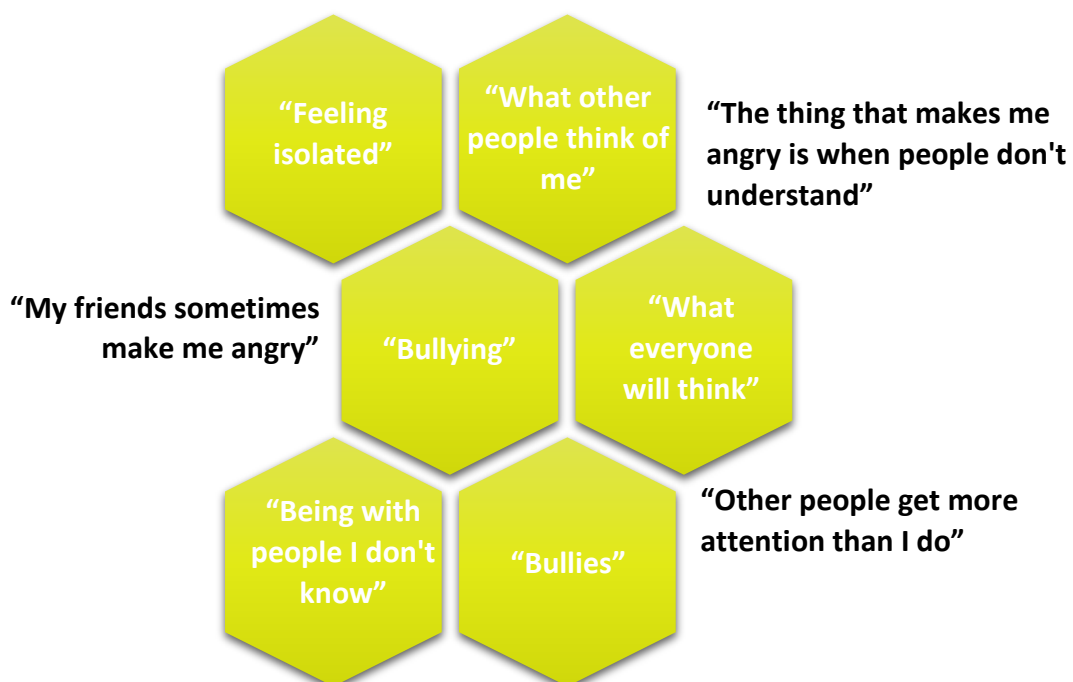
YC: Watch out for the bullies because they seem to, like, find out what's wrong, or that something's happened they'll try take advantage of it

I: How do you overcome that then?

YC: Just tell someone else, the teachers in my school don't really seem to help but you can speak to people who can

This sense of isolation from peers repeatedly emerged in the various workshops. Nine comments (of 66) in the **Worry Rocks** activity directly referenced issues surrounding bullying and social isolation or exclusion as being young carers' biggest anxieties:

Worry Rocks: Peer and social anxieties



In the **Timelines** activity, many young carers referenced tiredness, a lack of spare time to socialise or have fun with friends, and disengagement from peers and social activities. Many turned to video games, internet, and television as recreational activities in the home, often staying up late into the night to try and capture some enjoyable time to themselves after their daily tasks were complete.

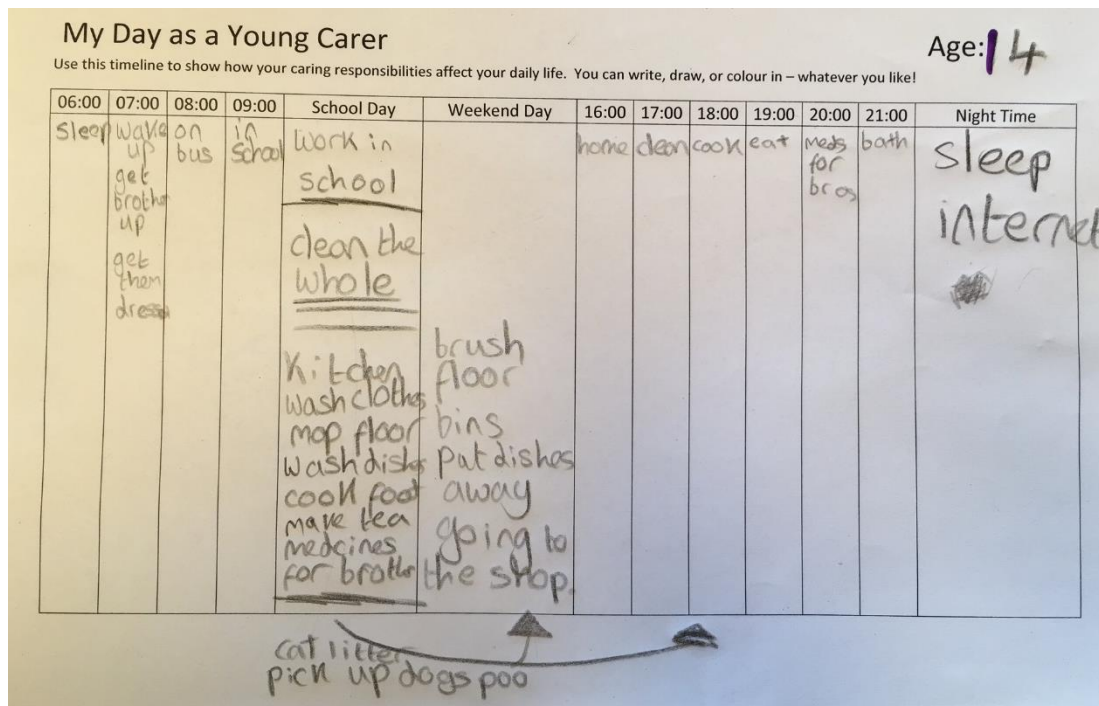


Figure 23: Timelines - A 14 year old carer's day

It seems that it is hard for young carers to turn to friends for support, and although families rated highly in the survey and workshops in terms of the support and understanding they offered, some workshop activities revealed ambivalence and contradiction in these relationships as well. While in the **Focus Groups**, the **Flower** activity, and the **Supporting Wall** data, a sense of closeness and mutual support within the family emerged as a positive aspect of being a young carers, the children and young people also faced increased relational difficulties within their caring relationships in terms of the emotional support and understanding that was demanded of them

Arguments and mutual frustrations in these relationships struck a chord with one **Focus Group** in particular:

YC1: There's loads of arguments with your family

YC2: You just get stressed out with each other

YC1: I take my anger out on my mum I feel sorry for her

YC2: I take my anger out on my brother

YC1: You've got so much on like school you've got so much and it just gets to you

YC2: Everything little gets to you

In terms of the advice that those in the focus groups would give to new young carers, several warned of the increased emotional demands of caring for someone who was often in physical or emotional pain themselves:

Emotional support is important. Like occasionally just checking up on them and making sure they're alright - finding a way to sort that out is one of the hardest challenges because sometimes you don't even know it

Be prepared for arguments - between yourself and the person you care for. Everyday nonsense because they're in pain. Being prepared to understand why this happens and not take it personally.

Feelings of pressure and their associated impact on young carers' mental and emotional wellbeing were frequently referenced in the workshops. In the **Letterbox** activity, many young carers ask the First Minister for more access to mental health services and increased control over their own lives.



These pressures are not only related to a lack of spare time or ability to socialise: one **Focus Group** discussant articulated the immense responsibilities of young carers and the very real and extreme pressures they are under through being responsible for other people's safety and health:

You need to understand what kind of tablets they need to take because if you give them the wrong tablets you could... kill them is a strong word, but hurt them.

Conclusion and Recommendations

From the workshop data and the findings from the survey that indicate a significant lack of support and understanding in everyday life, it is clear that many of the young carers in Cardiff and the Vale of Glamorgan are at significant risk of social difficulties and mental health issues, alongside the huge impact their role has on their education and future opportunities.

Given the extent of this risk for the present and future, the fact that the survey indicates that less than a third of young carers are receiving regular professional mental health support is very concerning.

Young carers reported feeling vulnerable in terms of bullying, social isolation from friends, financial resources, the emotional and physical demands placed on them, and having to cope with the responsibility for someone else's wellbeing and health. These vulnerabilities are not temporary and their ramifications will extend far into their futures.

The findings here echo those reported by the Mental Health Foundation (2010), which locate the risks for young carers as a lifelong burden:

Young carers do not cease to have caring responsibilities at age 16 or 18; the emotional and physical commitments remain. In finding employment, these young people are likely to be further disadvantaged in comparison with their peers because of interrupted schooling or poor attendance. Support that starts earlier and extends beyond the age of 18 would greatly improve these young carers' prospects in adult life.

- Mental Health Foundation, 2010: 28

Based on these findings, this report makes three key recommendations:

1. More effort must be made to raise awareness amongst all children and young people of what young carers do and the valuable contribution they make to society. A previously mentioned suggestion of running assemblies in school to accomplish this would be an ideal format, as would including it on the curriculum for citizenship or PSHE lessons. Teachers would need to receive the necessary support and resources to deliver this, and no individual carers should be identified within schools. It would be worth exploring the possibility of former young carers visiting schools to help in this education.
2. Ensuring that young carers have frequent, scheduled relief remains critical, and any increase in funding sources that would permit this support to be expanded would be extremely valuable.
3. All young carers should automatically be assigned contact with a counsellor or other professional mental health service. It may not be necessary for regular meetings to occur immediately, or, indeed, at any point, but some form of regular assessment must take place to identify and prevent the development of mental health issues.

SECTION 9: RESILIENCE, POSITIVITY, AND SOURCES OF SUPPORT

Finding Strength and Growing as a Young Carer

Thus far the findings from the survey and workshop data have related to negative experiences and the difficulties of being a young carer, however there is also much evidence that the positive work being conducted by the Young Carer's Project is having a big impact on their lives. Many young carers also identified benefits to their role, including closeness with family, making new friends in their fellow young carers, going on trips and learning new skills.

The value of the work that the Young Carer's Project is doing is clear in the data from the **Supporting Wall** exercise, where support workers and others they met through the project are celebrated by the young carers. The critical role that close and extended families play in their lives is also evident, though other people that they regularly come into contact with – like teachers and medical professionals – feature much less.

Another area of concern is how little friends were listed as sources of support, evoking the social isolation from peers observed in the previous section.

Table 4: Sources of Support

Support Groups & People	37
Mum	13
Family	10
Friends	11
Young Carers	8
School/college & Teachers	7
Grandparents & Aunts/Uncles	5
Siblings	4
Dad	3
Partner	3
Medical Professionals	2
Myself	2
Art	1
Music	1
Bank - financial help if needed	1
People close to me	1

Data from the **Washing Line** activity also shows that many children and young people – more than half – feel that being involved with the YMCA and the Young Carer's Project is the best thing about being a young carer.

Some typical comments here include:

Getting to go out on
more trips

Going out and having a
good time

Making new friends

Having the opportunity
to go out meet new
friends who understand
your situation

Knowing I'm not alone

The Young Carer's Project was not the only positive aspect of being a young carer reported in the **Washing Line** activity: many children and young people felt that the closeness and intimacy of their family life was a positive benefit of their role.

Typical comments include:

It got me more close to the people I love

More time with family

The house being happy

Being together as a family

I enjoy playing with my sister when she's bored

It was important to the young carers to engage with people and in activities that made them feel valuable, skilled, and that they enjoyed. These aspects of their lives were captured in the **Flowers** activity where the young carers recorded all the things in their lives that 'helped them to grow'.

The findings from this data are recorded in the table below, with the number of times each valued person/thing was mentioned recorded next to each category:

Table 5: Helping young carers grow

Family		Friends		Activities	
Family	10	Friends	21	Sport/Games/Exercise	17
Pets	9	Names	5	Performing Arts/Music	9
Mum	6	Boyfriend	2	Meals out	8
Siblings	5	Getting on with people	1	Holidays	6
Me	3	Young Carers	1	Gaming	6
Parents	2	Other activities		Going out	4
Dad	2	Food & Drink	18	Art	3
Brother achieving good things	1	Celebrity	10	Activities	3
Family being happy	1	Internet and media	17	Cooking	2
Relatives	1	Sweets/Chocs	8	Reading	2
Mother-in-law	1	Music	8	Motorbike	1
School & Work		Money	6	Photography	1
School & Education	4	Sleep	4	Support	
Jobs / Work	3	Alcohol	3	Learning new skills	6
Teachers	1	Cars	1	YMCA	3
PE	1	Play	1	Counselling	1
Science	1	Make-up	1	Transforum	1
Electronics	1	Flowers	1	Respite	1

In the **Focus Groups** young carers demonstrated a realistic approach to developing resilience and using support networks to inform their caring and reduce their social isolation.

Some discussants wanted new young carers to be prepared for how hard it was going to be, and advised developing resilience and patience as highly valuable skills:

"It's hard. You can't go in there thinking it's all going to be easy or something. You've got to understand that it is going to be hard"

"Take it as it comes, cos there's no point in trying to give people advice cos you don't know what their caring will be like. Make sure that everyone's ok, make sure the person you're caring for is ok, that everyone's looked after"

"Don't give up too easily. It will be difficult if you haven't cared for somebody before. It's nothing like in dramas"

Be patient, you need to try and build your patience. You won't have it straight away, it takes time and you need to work on it cos patience is a big thing of being a young carer.

You need confidence, because if you're not confident with the person you're with that you're caring for, you might stress out and mess up. You build confidence by practice, like if you're out with a friend talk with other people as well and tell them about who you care for and tell your friends as well. You get advice and people might come over and help you or get someone to come over and help you as well.

Others discussed how important it was to develop social bonds outside the immediate family, and how useful it was to meet people who understood about caring:

"Always try and talk to someone if it's getting too much. Cos even though there's quite a lot of us, it can get quite lonely, no matter what so I think if you get anyone from, you know, someone at school, a friend, someone in your family, make sure you let things out every so often"

"If you have a problem always go to a Young Carer (Project worker)"

"You can find others through the YMCA"

Conclusion and Recommendations

From the workshop data it is clear that the young carers involved in the Young Carer's Project are seeing significant benefit from the work they do and the socialising opportunities. It is not only the advice and relief that the service offers, but also the opportunities to gain new experiences and skills that they offer, with many children and young people speaking warmly about the trips they had been on and the activities they had tried.

The clear recommendation here is that it is critical for the project and others like it to be funded appropriately, and their existence promoted to a broader range of young people who may not be identified yet as a young carer. As one discussant in the focus groups recounted:

Yeah, like I didn't know I was a young carer until I joined Young Carers, until I was with FACT, and they were like, "Do you want to get assessed for it?" and I just thought this is what my life was like. It's what I'd had my entire life and I didn't know any different. There just needs to be more awareness about it.

Comments like this raise significant concerns about how many young carers are 'slipping through the net' and receiving no support or information at all regarding their responsibilities. Given what has been reported here regarding the mental health risks to young carers, this report strongly recommends wider promotion and resources relating to young carers being made available, with schools being the most obvious route through which this can take place.

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