

Young Adult Carers at College and University

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Summary



In 2013, Carers Trust commissioned the University of Nottingham to undertake research to examine the experiences and aspirations of young adult carers with regards to school, further and higher education, and work. A total of 362 people viewed the survey and responses from 295 young adult carers aged 14–25 were analysed. This is the third in a series of reports¹ to be published across 2013 and 2014 looking at issues related to school, college and university, employment, and those not in work or education.

In this report we explore the experiences and perceptions of 101 young adult carers who are in further and higher education, including those at sixth form college.

Young adult carers are often an overlooked group with limited services that meet their needs and little awareness among professionals and the wider public about the challenges they face.

There are over 375,000 young adult carers in the UK aged 14–25 who are providing support and assistance to their families and friends. Young adult carers take on significant additional responsibilities which can make the transitions from childhood into adulthood especially complex and challenging. The difficulties they experience as a result of their caring role can have significant and long-term negative impacts on their engagement with education and employment and their overall physical and emotional wellbeing.

The findings from this report reveal that despite high levels of caring many young adult carers go on to college or university. Once there however, they may experience considerable difficulties and many young adult carers consider dropping out because of their caring role. Issues with lateness or absence, balancing their caring responsibilities alongside their academic commitments and a high prevalence of self-reported mental health problems (45%), clearly indicate that young adult carers need to be identified early on and supported.

However, this report reveals that many young adult carers are left struggling to complete their courses without adequate support. Over three quarters of the young adult carers in this survey had communicated their caring role to their college or university, but nearly half (45%) still felt there was no one there who recognised them as a carer and helped them. In their caring roles, only a minority had received a formal assessment of their needs and almost a third (30%) reported that their family was not receiving good services and support.

1 Sempik, J and Becker, S (2013), *Young Adult Carers at School: Experiences and Perceptions of Caring and Education* (London, Carers Trust); Sempik, J and Becker, S (2014), *Young Adult Carers and Employment* (London, Carers Trust).

Young adult carers should have the opportunity to fulfil their potential and reach their own goals. This report reiterates that appropriate care and support is required for the person with care needs to allow all young adult carers to fully participate in education. The findings also highlight that colleges and universities must do better to respond to the individual needs of young adult carers to enable them to maintain their education and live healthily.

Summary findings

- The 101 young adult carers who were in further or higher education showed that on average they provided a ‘Very high’ level of care².
- 39% rated their physical health as either ‘Just OK’ or ‘Poor’; and 45% reported having mental health problems.
- Despite most respondents (79%) enjoying college or university, over half of them (56%) were experiencing difficulties because of their caring role. 16% were concerned that they might have to drop out of college or university.
- Those who reported that they found college or university difficult had significantly higher caring responsibilities.³
- 75% of respondents informed college or university staff of their caring role. Despite this, 45% said there was no one who recognised them as a carer and helped them. Of those who did not inform college or university staff, the main reason for not doing so was that there was “no point”.
- The majority of respondents (62%) had not had a formal assessment by a social worker or other health/social care professional. Almost a third (30%) believed they had not received good services as a young carer or adequate support for their families (31%).
- 56% of respondents received a bursary to help with their studies, including 12 of the 17 at university. Only four respondents (4.6%, n=87) received Carer’s Allowance, and 13 (21%, n=62) were in receipt of some other form of benefit.
- 60 of the respondents were currently attending a young carers or young adult carers service. Of these, almost all (95%) felt that their confidence had improved as a result and that they had more friends (87%).

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- 2 The survey questionnaire included the psychometric MACA tool, Joseph et al (2009), *Multidimensional Assessment of Caring Activities* (London, The Princess Royal Trust for Carers). The tool is used to measure the extent of caring provided by young people. Overall, the mean caring score (MACA) of the entire sample of respondents was 18.1, showing that they provided a ‘very high’ level of care.
 - 3 MACA score of 19.5 compared with 16.7.

Recommendations



Schools and sixth form colleges

Targeted careers advice should be available to young adult carers which addresses their caring responsibilities, recognises any additional skills they have developed in their caring role and supports them to consider all available options.

Schools and sixth form colleges should provide a balanced view of courses and subjects and encourage young adult carers to think broadly about their ambitions and aspirations.

Health and wellbeing

Student health and welfare services need to recognise the physical and mental health needs of young adult carers at college and university and prioritise them for support. They should make explicit the services and support that are available and how they can be accessed. There is a need for 'joined up' services that involve both academic and health and welfare services so that support is provided in an holistic fashion.

Formal procedures should be available within colleges and universities so that young adult carers can inform staff of their caring roles. Support services should be clearly visible so that young people feel that there is a point in informing staff.

Study

Colleges and universities should develop policies and procedures that identify young adult carers who are having difficulties with their academic work and provide timely and appropriate support.

Colleges and universities should develop awareness training for their staff so that they understand the difficulties faced by young adult carers and know how to identify and support them effectively.

Financial support

Guidance should be developed to help young adult carers who are going to college and university to apply for any bursaries, benefits or financial support for which they are eligible.

Support and services

In order for the young adult carer to participate fully in education, the care and support needs of the person being cared for should be adequately met.

Young adult carers must receive an appropriate assessment which takes into account their wishes to participate in education and the impact of the caring role upon their desire and ability to do so.

Colleges and universities, and their health and welfare services including student unions, have a role to play in ensuring that young adult carers receive proper assessment and, subsequently, appropriate services.

Colleges and universities should make closer links with local young adult carers services so that students with caring responsibilities are aware of the support they could receive. Local student unions have a role to play in disseminating information about the services and should consider starting and promoting college-based support where appropriate.

Background



The notion of a young adult carer was first identified and proposed by Becker and Becker (2008). This group includes those young people who are aged between 14 and 25. This is a time of transition and decision for young people. The decisions they make and the achievements they show at college and university will shape the rest of their lives.

Research has shown that young people with caring roles often achieve lower grades than their non-caring peers because of disruption caused by being carers (Aldridge and Becker, 1993, 2003, Dearden and Becker, 2002, 2004). This may prevent many of them from even going to college or university. However, for those who have been able to go on to further or higher education, there are often other struggles and hardships ahead.

Going to college or university can be a stressful experience for many young people. However, for those with caring responsibilities it can be even harder to meet deadlines for assignments and essays; harder to find the time to make friends and be accepted; and more difficult to commit themselves fully to college life. A recent survey⁴ by the National Union of Students showed that only 36% of student carers felt able to balance their commitments, compared with 53% of students without such responsibilities.

In some cases, college or university staff are not aware of young people's roles as carers and no additional support is provided. Young adult carers may also not want to share their experiences with anyone else, and prefer to keep their private lives private.

It is important to understand the challenges that young adult carers face when they go to college or university, and how their caring roles have an impact upon their academic work, and on their chances of finding suitable employment when they complete their studies. By understanding these difficulties, it will be possible to provide the support that they need to help them through college and university and onto the path towards a fulfilling career in which they can achieve their true potential.

4 www.nus.org.uk/Global/NEW%20Carers%20research%20report%20WEB.pdf

The survey

The data were collected as part of an online survey of young adult carers conducted from April to August 2013. A total of 295 respondents provided information that was valid for inclusion in the analysis. Data were analysed using the statistical package SPSS, and parametric tests (ANOVA and t-test) and non-parametric tests (Chi Squared) were used as appropriate. We have previously analysed and published data from those still at school (Sempik and Becker, 2013), and those in employment or NEET (Sempik and Becker, 2014). This report deals with those 101 respondents who were in further or higher education, including those at sixth form college.

The sample

58% of all respondents in the sample were on full-time courses and 5% on part-time ones, the remainder did not provide information about their course. The mean age of the sample was 18.5 (SD 1.9) and the majority (82%) of respondents were female. The female respondents were slightly older (18.6, SD 1.9, n=80) than the males (17.7, SD 1.1, n=17), but the difference was not statistically significant ($p=0.06$).

Most respondents (50%) cared for their mother. The mean age at which they had started to care was 10.2 (SD 3.7; n=86), in other words, they had spent almost half of their young lives in a caring role, and had been carers throughout their time at secondary school – the time at which they had studied for, and taken their exams.

The survey questionnaire included the Multidimensional Assessment of Caring Activities (Joseph et al, 2009), a psychometric tool used to measure the extent of caring provided by young people. This psychometric instrument is used extensively to score the caring roles of children and young people. Levels of care provision are categorised as 'Low' (MACA score <9), 'Medium' (10–13), 'High' (14–17) and 'Very high' (18 and above). Overall, the mean MACA score was 18.1 (SD 5.4; n=101) indicating a 'Very high' level of caring among respondents in this sample. Half of the respondents were providing a 'Very high' level of care, and only three, a 'Low' level (see table, below).

Care levels experienced by young adult carers

Care level	Number	%
Very high	51	50.5%
High	30	29.7%
Moderate	17	16.8%
Low	3	3.0%
Total	101	100

There were no statistically significant differences in MACA scores between respondents at sixth form college, college of further/higher education or university.

The most common disability or condition of those cared for by the young adult carers in this sample was a long-term illness (63%) which also included terminal illness; 59% cared for someone with a physical disability, and 52% for someone with mental health problems. 26% cared for someone with a learning disability or autism, 12% for an older person and 9% for someone with drug or alcohol problems. Seven respondents in the sample cared for someone with dementia.

More information about the sample is provided in the Appendix.

About Carers Trust

Carers Trust is a major new charity for, with and about carers. We work to improve support, services and recognition for anyone living with the challenges of caring, **unpaid**, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems.

We do this with Network Partners – a unique network of 116 independent carers centres, 59 Crossroads Care schemes and 105 young carers services.

Together we are united by a shared vision for carers – to make sure that information, advice and practical support are available to all carers across the UK.

Research findings



Young adult carers' own health

This series of reports reveals a high prevalence of self-reported mental health issues in the sample of young adult carers, regardless of whether they are in education, employment or neither.

Nearly half (45%) of the respondents in further and higher education who were asked to rate their own physical health and to identify any specific issues, reported having mental health problems. This reflects previous findings (Sempik and Becker, 2013, 2014) that 38% of young adult carers in schools, and between 51% and 61% who were in work or NEET reported having such difficulties.

39% rated their physical health as either 'Just OK' or 'Poor', and 20% reported having a physical disability. This corresponds with 2011 Census data which showed that children aged 5–18 who provided unpaid care were more likely than children with no caring responsibilities to report their perceived general health as 'Not good'. Those who spent 50 or more hours per week caring were up to five times more likely to report their health as 'Not good'⁵.

While these findings do not necessarily show a causal relationship, having mental or physical difficulties is likely to make caring more difficult and create additional complications for studying at college or university.

Perceived state of physical health of young adult carers in college or university

Perceived state of health	Number	%
Very good	12	11.9%
Good	50	49.5%
Just OK	32	31.7%
Poor	7	6.9%
Total	101	100

5 2011 Census (www.ons.gov.uk/ons/rel/census/2011-census-analysis/provision-of-unpaid-care-in-england-and-wales--2011/sty-unpaid-care.html)

Health issues reported by young adult carers at college or university

Perceived state of health	Number	%
Mental health problems	45	44.6%
Physical disability	29	28.7%
Dyslexia	28	27.7%
Sensory difficulties	11	10.9%
Learning difficulties	6	5.9%
Asperger's or autism	4	4%
Total	101	100

Recommendation: student health and welfare services need to recognise the physical and mental health needs of young adult carers at college and university and prioritise them for support. They should make explicit the services and support that are available and how they can be accessed.

Experiences of college or university

The survey responses showed that most young adult carers (79%) enjoyed college or university and thought they were doing well (69%). However, over half of the respondents (56%) were experiencing difficulties because of their caring role.

Those who found college or university difficult had significantly greater caring responsibilities than those who did not⁶.

Those who provided a 'Very high' level of care were more likely to have difficulties at college or university than those whose care level was 'High'.

14 of the respondents (16%, n=86) were concerned that they might have to drop out of college or university. Of these, 11 (79%) provided a 'Very high' level of care, and three, a 'High' level. Despite the difficulties faced by these young people, less than half (46%) of the whole sample reported that they had a particular individual who helped them.

6 The mean MACA score of those who experienced difficulties was 19.5 (SD 5.6, n=50) compared with 16.7 (SD 5.0; n=28) for those who did not experience difficulties (p=0.03).

This shows that a higher level of care leads to difficulties in coping with the demands of a college or university course and suggests that these young people are not receiving adequate support to help them in their caring role and with their academic work.

Young adult carers' experience of college or university

	Yes	%	No	%	Not sure	%	Total
I enjoy college or university	72	79.1	12	13.2	7	7.7	91
I am doing well at college or university	62	68.9	12	13.3	16	17.8	90
I find college/ university difficult because of my caring role	50	55.6	28	31.1	12	13.3	90
There is a particular person at college/ university who recognises I am a carer and helps me	41	46.1	40	44.9	8	9.0	89
I may drop out because of my caring role	14	16.3	53	61.6	19	22.1	86
I may drop out because of financial difficulties	11	12.5	66	75.0	11	12.5	88

Recommendation: colleges and universities should develop policies and procedures that identify young adult carers who are having difficulties with their academic work and provide timely and appropriate support.

Recommendation: colleges and universities should develop awareness training for their staff so that they understand the difficulties faced by young adult carers and know how to identify and support them effectively.

Reasons for choosing the college/university and the course

The great majority of respondents (83%) chose their course because they enjoyed the subject; just over half (54%) thought it would provide them with good prospects for employment; and for 44%, the proximity of the college or university was an important factor. Therefore, the main driving factor in their choice appears to be the subject itself, although for many the closeness of the institution was a factor (so that their caring role could be made easier).

Reason for young adult carers choosing college/university course

	N=101	
Reason for choosing college/university course	Number	%
Like the subject	84	83.2
Good employment prospects	54	53.5
College is near	44	43.6
Good at subject	39	38.6
Advised by teacher	20	19.8

Of the 68 respondents who supplied information about their course, a third (32%) were studying on a course that was classed as 'caring'. This included health and social care, childcare, social work and occupational therapy. A further four students were studying psychology at university – an option that could lead to a caring employment role, for example, in counselling or psychotherapy. These young people's experiences as carers may well have influenced their decision in their choice of subject and directed them towards the caring professions. The transferable skills that they gained within their caring role may, therefore, be put to good use later on. However, one important question that needs to be answered is whether their experiences as carers have dominated their viewpoint and prevented them from seeing alternative career paths.

These young people need expert career advice that is sensitive to their position and which is able to present a balanced view of different courses and careers. But only a minority of respondents (20%) cited the advice of a teacher as a reason for choosing their course; and only a minority (22%) reported that they had received good career advice at school; and even fewer (12%) reported that their career advice had taken their caring role into account.

Recommendation: targeted career advice should be available to young adult carers which addresses their caring responsibilities, recognises any additional skills they have developed in their caring role and supports them to consider all available options.

Recommendation: schools and sixth form colleges should provide a balanced view of courses and subjects and encourage young adult carers to think broadly about their ambitions and aspirations.

Bursaries, benefits and additional employment income

Bursaries and scholarships

41 respondents (56%, n=73) received a bursary; and four (4.6%, n=87) received Carer's Allowance; 13 (21%, n=62) were in receipt of some other form of benefit. Of those at university (n=17), 12 received a bursary; two, Carer's Allowance; and one, some other form of benefit.

While it appears that a large proportion of the young adult carers received a bursary to help them with their studies, it is likely that many more could be eligible for such grants. Colleges and universities should make information about such bursaries accessible and young adult carers should be able to receive appropriate guidance and support to identify bursaries for which they are eligible and to help them with the application. Young adult carers projects and national support organisations have a role to play in drafting such guidance. The same is true for benefits. Only a very small number of respondents were in receipt of benefits. More guidance and advice is needed so that the young people can claim benefits to which they are entitled.

Recommendation: guidance should be developed to help young adult carers who are going to college and university to apply for any bursaries, benefits or financial support for which they are eligible.

Additional employment

42% of respondents had a part-time job to provide additional income (n=101); seven of the 17 who were at university were in employment. The time worked ranged from 2–25 hours per week, and some were on flexible or zero hours contracts. The type of employment varied from part-time waitressing to busking. However, for some the demands of the course were too great to take on work even though they may have thought the income would have been useful.

There was no statistically significant difference in MACA score between those who had additional employment (18.6; SD 5.9) and those who had not (17.7; SD 5.0) (p=0.396; n=101). Even some of those young adult carers who provided the highest level of care also worked to earn some additional income.

Recommendation: research is needed to investigate the financial needs of young adult carers at college and university and to explore all of their reasons for taking on additional part-time work.

Informing staff and friends of their caring roles

Just under two thirds (62%) of respondents reported that their friends knew they were carers but only 28% thought that their friends treated them well as a result of this knowledge. Unlike the experiences of young adult carers at school, where 25% of young adult carers were bullied for being a carer (Sempik and Becker, 2013), bullying was not a widespread issue for those at college or university. Only a small number of respondents (5) reported that they had been bullied because they were carers and none of these were at university. Any level of bullying is unacceptable and colleges and universities should make their anti-bullying policies explicit and establish procedures that protect these young adult carers from abuse and make it clear how they can report any concerns or issues.

Experiences of young adult carers informing staff and friends of their caring roles

	Yes	%	No	%	Not sure	%	Total
My friends at college/ university know I am a carer	56	61.5	30	33.0	5	5.5	91
My friends at college/ university treat me well because I am a carer	24	27.6	44	50.6	19	21.8	87
I have been bullied because I am a carer	5	5.7	74	85.1	8	9.2	87

75% of respondents (n=88) informed college or university staff of their caring role; of those who did not inform staff (n=22), 16 considered there “was no point”; 12 reported that “no one asked”; 11 did not know “who to tell”; and nine “wished to keep it private”. Of those at university, ten (59%) informed staff of their caring role. As reported previously (Sempik and Becker, 2013, 2014), the feeling that ‘there is no point’ in telling staff of their caring role is the main reason why some young people do not inform college and university staff – and potentially miss out on support. Procedures for informing staff and the ensuing support services need to be clearly visible so that these young people feel that there is a point in telling others that they are carers.

Three quarters of the young adult carers had informed college or university of their caring role, which makes the finding that 56% of them were experiencing difficulties at university even more stark. Despite the colleges being informed and the young adult carers experiencing difficulties relating to their caring, 45% of them reported that there was no one there to help them. It is unsurprising therefore, that the main reason young adult carers do not communicate their caring responsibilities is because they see no point in doing so.

Recommendation: formal procedures should be available within colleges and universities so that young adult carers can inform staff of their caring roles. Support services should be clearly visible so that young people feel that there is a point in informing staff.

Absence and lateness because of caring

On average, the respondents in the sample had missed one and a half days in the previous two weeks because of their caring role and had been late a similar number of times. There were no statistically significant differences between respondents at sixth form college, college of further/higher education or university in the number of days missed, times late, times they had to leave early or times called away.

Young adult carers in this survey lost a substantial amount of college and university time because of their caring role. On average, a total of 4.8 days in the previous fortnight – half of the time spent at college or university – were compromised due to their caring role. Thus, caring has a negative impact on almost half of the time they are at college and university. What was not measured by this survey was the extent to which their private study time was also affected. But as mentioned above, over half of the respondents reported that they experienced difficulties at college or university because of their caring role.

There was a weak to moderate but statistically significant correlation⁷ between the total MACA scores and the measures of absence and lateness. This suggests that those with greater caring responsibilities are more likely to miss days from college or university than those with lesser responsibilities; and to lose time through being late or being called away.

Recommendation: in order for the young adult carer to participate fully in education, the care and support needs of the person being cared for should be adequately met.

Support and assessments

The majority of respondents (62%) had not had a formal assessment by a social worker or other health/social care professional; and almost a third (30%) believed they had not received good services as a young carer or adequate support for their families (31%).

7 The value of the correlation coefficient (r) ranged between 0.29 and 0.41 depending on the measure of absence and lateness. Dancey and Reidy (2004) suggest that values of Pearson's r of 0.1–0.3 are 'weak' correlations; 0.4–0.6 represent 'moderate' correlations; 0.7–0.9, 'strong' correlation. 1 is a perfect correlation.

Only a minority of young adult carers' needs are being assessed, and there is a substantial proportion of young adult carers at college and university who are not receiving appropriate support and services. As we have commented previously (Sempik and Becker, 2014), if the respondents are representative of the population of young adult carers in the UK, then over 200,000 young people are not receiving the services and support that they need.

Services and assessments for young adult carers

	Yes	%	No	%	Not sure	%	Total
Received good services as a young carer/young adult carer	49	53.8	27	29.7	15	16.5	91
Family receives good support and services	38	41.8	28	30.8	25	27.5	91
Had a formal assessment by social services/ social work department	20	21.7	57	62.0	15	16.3	92

There is a role for student health and welfare services to be proactive in ensuring that young adult carers at college and university receive proper assessments and the support and services that they need. Other academic services and organisations, for example, local student unions, can also help by raising awareness and disseminating information.

Recommendation: colleges and universities, and their health and welfare services, including student unions, have a role to play in ensuring that young adult carers receive proper assessments and, subsequently, appropriate services.

Recommendation: young adult carers must receive an appropriate assessment which takes into account their wishes to participate in education and the impact of the caring role upon their desire and ability to do so.

Support from young carer and young adult carer services

Of all the respondents, 60 (of 101) were currently attending a young carers or young adult carers service.

Benefits of attending a young carer or young adult carers service⁸

	Number	%
I am a more confident person	57	95.0
I have more friends	52	86.7
I attend college/university more often	32	53.3
I do better at college/university	29	48.3
I receive more help in my caring role	20	33.3
I have found a job	15	25.0
I do less caring	9	15.0

The greatest impact of the services was on the young people's confidence and social interaction. Almost all (95% and 87%, respectively) reported that they were more confident and had more friends as a result of attending a project. Going to university or college is a daunting experience, and despite the social opportunities on offer, many young people feel isolated and alone. For those with caring responsibilities, where much of their free time is spent looking after someone, the potential for social isolation is greater. Young adult carers projects offer a particularly important and valuable service. However, participation in such projects is relatively low. Even though this sample of respondents was assembled through a network of young carers and young adult carers projects, 40% did not attend a project. This reflects the lack of provision available to support the specific needs of young adult carers in the UK.

Recommendation: colleges and universities should make closer links with local young adult carers services so that students with caring responsibilities are aware of the support they could receive. Local student unions have a role to play in disseminating information about the services and should consider starting and promoting college based support where appropriate.

⁸ Percentages of 60 who were currently attending a young carer or young adult carers project.

Conclusion



This study shows that many young adult carers undertaking very high levels of caring still endeavour to pursue their education by attending college and university. Indeed, our previous work (Sempik and Becker, 2013) has shown that 95% of young adult carers at school would like to go college or university. However, once there, over half of them experience difficulties and as many as 16% of them are concerned they will have to drop out. For the young adult carers in this survey there was a direct correlation between the level of their caring responsibilities and how difficult they found college or university.

The research findings provide some insight into the difficulties experienced by young adult carers including the high occurrence of absence and lateness which has an impact on their ability to keep up with their course and workload. In total, almost half of their time at college or university was affected by their caring role – either through being absent, being late or being called home. There was a significant correlation between the extent of caring (as measured by the MACA score) and absence and lateness, suggesting, that the greater the level of care, the greater the impact on attendance and the consequent damage to their education.

The prevalence of mental health problems, reported by almost half of the young adult carers, and the large proportion (39%) reporting their physical health as 'Just OK' or 'Poor' also shows that many young adult carers at college and university are coping with their own physical and mental health problems in addition to providing care and trying to keep up with their courses.

What is stark about these findings is that 75% of the young adult carers who responded had communicated their caring role to their college or university, but 45% said there was no one who recognised them as a carer and helped them. With over half of them experiencing difficulties, this highlights that more needs to be done by colleges and universities to reduce barriers to education.

Colleges and universities not only have responsibilities for providing academic support, they also provide health and pastoral care for their students. They have a responsibility for the wellbeing of their students. For young adult carers, issues around academic success (or lack of it), mental and physical health and caring roles are all intertwined and can easily create a vicious circle. The care and support that young adult carers require needs to be coordinated and should involve academic services, student health and welfare services, local student unions and others. Student health and welfare services should be proactive in ensuring that young adult carers at college and university receive suitable services and support is provided.

Caring responsibilities are having a negative impact on the education of half of the young adult carers in this sample, but only a minority (22%) had received a formal assessment, and almost a third (30%) reported that their families were not

receiving good support and services. Appropriate support needs to be put in place for the person being cared for so that young adult carers can fulfil their own potential. Young adult carers must be protected from taking on inappropriate caring roles which prevent them from engaging in education and realising their own goals. Adults and children's social services, and health and education providers must work together to ensure that young adult carers are not relied upon to provide excessive care and support, that their own health is safeguarded and access to education is promoted.

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Case studies



Jane is 24. She has a degree and is at university studying for a Master's. She cares for her mother, who has cancer, and for her elderly grandparents. She has been caring since her mother was diagnosed with cancer two years ago.

She describes her physical health as 'Just OK', and reports that she suffers from mental health problems and has a physical disability. She also has dyslexia.

Her MACA score is 17, showing that she provides a 'High' level of care. She spends up to 50 hours caring in the week and up to 20 at the weekends.

There is no aspect of caring that she says that she likes:

"I don't like doing any of them [caring tasks], because I find it really painful to need to care for the people I care about and look up to that way. But the best is always when you have a rewarding conversation, it forces you to acknowledge how much you love each other."

The need to provide care and to deal with the consequences of people who require care are ever present in her life:

"Not a 'job' so much as the fact that you can't escape it when there is someone who needs constant care in your home, your house is no longer your own; the most telling for me is I can't just go to the toilet anymore – I often have to clean it first, that there is faeces on the seat or the sink or the toilet roll or door handle, and that signifies for me the worst bit about care, you can't just do the things you normally do, you always have to think and act for others first."

While she has coped with all of the physical demands of caring, when her mother became ill and needed chemotherapy, Jane, found the experience of her mother's treatment especially traumatic.

"The one I couldn't cope with at all was going with my mum to get her chemotherapy treatment; I just wasn't strong enough to take that, and she ended up supporting me more than I could support her, because it upset me so much to see the needle pumping poisonous chemicals into her that would make her feel awful, and to be faced with her illness and mortality like that was just too much for me."

In addition to caring for her grandparents and mother and going to university, Jane also has a part-time waitressing job for 4–8 hours each week. Jane has never had a formal assessment of her needs, and says that she does not receive good services to support her or her family.

John is 19, and in his third year studying professional cookery at a college of further education. He hopes to be a chef.

He cares for his mother who has sensory and physical disabilities and has been caring for her for the past three years. He finds it hard to estimate the time during the week he spends caring for his mother, but it occupies much of his time when he is not at college:

“It’s hard to work out the exact hours but I look after my mum around my college hours.”

At the weekend he spends most of his time caring:

“Mostly all the time unless working, so 48 hours.”

His MACA score of 20 shows that he provides a ‘Very high’ extent of care, and he says: “There is no job I dislike as I love my mum and helping her in any way I can”. He enjoys taking his mother out for something to eat or just a drink, but he can’t afford to do that too often:

“Being able to take my mum out either for a drink or something to eat as I can’t always afford it and I only have my mum in my life so I try to take good care of her.”

When asked what he finds the most upsetting, he responds like many other young adult carers that seeing the person they care for in pain or distress is the most difficult aspect of caring:

“Seeing my mum in pain as she is unable to do anything.”

John receives a bursary from college, and also has a part-time job to earn additional income. Like many other young people, he works flexible hours on a zero hours contract and says: “I have no set hours of work as I work part time and get called in as and when needed.” Like Jane, John has to balance his college work, caring responsibilities and a part-time job; and like Jane he has never had a formal assessment.

Appendix

The sample

Age and gender of all respondents

Gender	Number	%	Mean age (years)	SD
Female	82	82.0%	18.6 (n=80)	1.9
Male	18	18.0%	17.7 (n=17)	1.1
Total	100	100%		

Current position of respondents

	Number	%
At university	17	16.8%
At sixth form college	33	32.7%
At a college of further/higher education	51	50.5%
Total	101	

Number of individuals for whom care is provided

	Number	%
One	64	63.4%
Two	28	27.7%
Three	3	3.0%
Four or more	6	5.9%
Total	101	100%

Who they care for

Person cared for	Number	%
Mother	50	50.0%
Father	19	19.0%
Brothers/Step brothers	13	13.0%
Sisters/Step sisters	10	10.0%
Grandparents	5	5.0%
Other relative	2	2.0%
Step father	1	1.0%
Total	100	100%

Conditions of those cared for

Disability or condition of person cared for	Number	% (n=101)
Physical disability	60	59.4%
Mental health problem	52	51.5%
Long-term physical illness (including terminal illness)	64	63.4%
Learning disability or autism	26	25.7%
Older people	12	11.9%
Drug or alcohol problems	9	8.9%
Behavioural problem	17	16.8%
Dementia	7	6.9%



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Please note, identities of carers have been changed in the interests of privacy.