

YOUNG CARERS REPORT

FOOD FOR THOUGHT



JUNE 2018

VOICES
NORTHUMBERLAND

Northumberland
Northumberland County Council



Part 1 - Introduction

Purpose of this report

This report, 'Food for Thought', April 2018, is the fifth annual report produced by VoiCeS Northumberland that has presented the voice of young carers in Northumberland. It builds on previous reports; '[First Steps](#),' September 2014 '[Our Voice](#)', May 2015; '[What's Ya fettle](#)', May 2016 and '[Is Anybody Listening](#)', April 2017.

Previous reports have highlighted to voices of young carers in Northumberland by listening to their experiences and how their caring responsibilities impact their lives, actively involving them in opportunities to affect change and enhance good practice at both local and county levels.

This report presents the findings of two separately funded pieces of work, one commissioned by Northumberland County Council (NCC) and the second commissioned by Carers Northumberland funded by the Pears Foundation via the Carers Trust.

The work was delivered by **VoiCeS Northumberland** under three distinct but inter-related areas:

Offering Involvement - using healthy eating and cooking skills as a vehicle to engage with groups of young carers and hear their voices. This work culminated in a mini food festival.

Listening - to young carers voices. Four case studies, focus groups and discussion on health related matters and facilities in Northumberland.

Raising Awareness - presenting the voice of young carers through a co-produced a social media campaign.

Who are VoiCeS Northumberland?

Voices Northumberland is a Voluntary and Community Sector Organisation (VCS); the only Northumberland based VCS organisation dedicated to supporting VCS organisations that work with children, young people and families.

We offer advice and training tailored to the responsibilities and needs of organisations to ensure safeguarding and protection of children and young people. We aim to promote social justice and raise awareness of the issues young people often face as a result of social exclusion, poverty and deprivation.

We are committed to providing a platform for children and families voices to be heard. We are passionate about advocating on behalf of young people, in order to further develop effective and person centred ways of working and ensure good practice across the sector.

We have contributed to the Young Carers Action Group, The Carers Partnership. We have been involved in the development of the Young Carers strategy action plan and we work in partnership with other VCS providers to contribute to strategic planning groups such as The Health and Wellbeing Board and Northumberland Safeguarding Children Board, thus ensuring the voices of young carers are represented at local and county level.



Who is a Young Carer?

There are a number of different definitions of the term 'young carer', but throughout this report we will be using the denotation preferred by NCC.

'A young carer is anyone under the age of 18, whose life is in some way restricted because they provide, or intend to provide, care of any family member who is physically or mentally ill, frail, elderly, disabled or misuses alcohol or substances. This memorandum also applies to young adult carers aged up to the age of 25, encompassing the transitions from children's services to adult care and support. Many young carers assume significant levels of responsibility normally associated with an adult. It should not be assumed that all children whose parents are ill or disabled are automatically young carers, however, research tells us that living with a disabled or ill person increases vulnerability in children and we therefore aim to minimise any negative impact of caring responsibilities on the child or young person' (NCC, 2015)

What is the Local Context?

Figures from the 2011 census indicated that approximately 6% of young people in Northumberland may provide unpaid care. The report 'Young people in Northumberland' (NCC 2015) gave the same figure of 6% of young people who regarded themselves as carers, however, a further 6% said they were unsure if they were a carer or not. The Carers Trust estimate some 700,000 young carers in the UK, approximately 1 in 12 of young people. Government figures show a steep rise in the number of young carers over the past few years particularly in the 16-17 age group (Independent, 2018).

Young carers are often a hidden group and it is therefore difficult to get accurate figures for the number of young carers in Northumberland (Northumberland Joint Commissioning Strategy, 2013-2016). 'Recognised, valued and Supported: Next Steps for the Carers Strategy' (Department of Health, 2010) acknowledged that many young carers remain 'hidden' from health, social care and education services. It noted that this is partly because services need to do more to identify them, but also because families fear that the children will be taken into care if the situation is exposed. In addition young people themselves are concerned about stigmatisation from others and bullying by their peers (Social Care Institute for Excellence [SCIE] 2005). As a consequence it is reasonable to assume that the actual figure of young carers in Northumberland is likely to be considerably higher than the reported 6%.

The Wider Context

Since the introduction of the Care Act and The Children and Families Act 2014, local authorities have a duty to consider the needs of young carers and their families. The main points of the Children and Families Act are:

- The starting point is always 'children are children first'
- Local Authorities must offer an assessment where it appears that a child is involved in providing care
- Identifying if care is excessive or inappropriate
- Does the caring role affect the child's wellbeing – physically, emotionally, psychologically
- Anyone carrying out the assessment must take a whole family approach and consider other siblings and the wider family too.
- Each young person should be treated as an individual.
- The welfare of the child is paramount. They should be safeguarded from abuse or neglect
- Particular attention should be given to children who are caring for a parent – they should not be undertaking a 'parental' role.
- It is important to separate the child's understandings and wishes from the adults in the child's network.
- Assessment could take the form of a 'together, apart, together' method. Bringing the family together initially, then working individually with each member and coming back together as a group.
- A record should be kept of the assessment and the agreed plan. This should detail the contribution, roles and responsibilities of service providers to the young carer. The young carer should have a copy of the plan in an accessible format.
- The plan should be reviewed on a regular basis
- The Care Act introduces new duties for Local Authorities to offer transition assessments to young carers reaching eighteen
- Transitions assessments must place the needs of the young person at the heart of the process and focus on their future aspirations.
- Transition assessments should include information on family relationships, social support, education and training, accommodation, health and wellbeing and financial literacy
- If an authority decides it will not provide a transition assessment, it must provide a written explanation to the young carer and their parents.

Acknowledging and recognising the importance of the key points in the Children and Families Act, enables us to frame the discussions we have with young carers and the experiences which they share with us, identify safeguarding issues and helping to ensure we foreground their voices.

As part of the work, Voices Northumberland designed a card outlining information about Early Help Assessments (EHA's) for young carers and who to contact. These cards were given to support workers at young carer groups and were also placed in individual food factor folders.

What did we do?

We worked with two young carer support groups – one at Berwick and the other at Cramlington. We set up a number of interactive sessions with young carers between October 2017 and March 2018. These sessions included informal discussion groups, one to one interviews to create four case studies, cookery and healthy eating activities, design and participation in a mini food festival, photography sessions and involvement in production and design of posters and memes for a social media campaign. We spoke to thirty young carers and volunteers, and support workers across both groups.

In order that young carer voices are heard, we have worked with the groups over a number of years to build up a relationship of trust. It has also enable us to gain a better understanding of how carer roles evolve as the young person grows up, the needs of the person/s they care for change, how support can vary from primary to secondary schools, and the additional demands placed on young carers as they face GCSE's, A-levels and the prospect of leaving home or going into further education.

The carers views are sought at all stages and their participation in the project, including the use of their words and photos in printed materials, such as this report, are only used with their express consent. Parents also give consent prior to any activities taking place. We are aware of the many demands placed on young carers, and we are mindful of the time which they give us in order to conduct research. Acknowledging this, as best practice, ensures we are careful not to place further additional burdens on their time. Some young carers were happy to engage for longer sessions, some participated more minimally, and others chose not to engage. We welcomed the advice provided by support workers at both groups, which helped to ensure the sessions were safe and enjoyable



Part 1: Offering Involvement - The Food Factor

Using funding from The Pears Foundation and Carers Trust, via Carers Northumberland we delivered a five month project around well-being and healthy eating for young carers in Northumberland – called the Food Factor. The project included cookery lessons across a number of weeks, food preparation and food hygiene. The project closed with a mini food festival at Cramlington Voluntary Youth Project on 3rd February 2018.

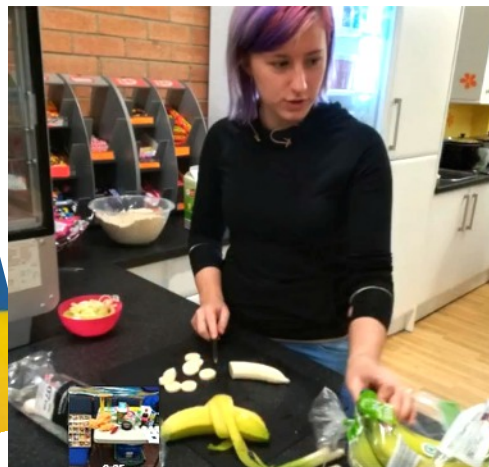


The aim of the project was to teach young carers some basic cooking skills and learn about healthy eating by having fun in the kitchen.

The first session was held at Berwick Sure Start Centre in October. A Halloween theme was used to deliver a fun interactive session for the young carers. They ducked for apples, made pumpkin lanterns, got slightly messy finding sweets hidden in icing sugar and decorated with cooked pasta. We also provided a selection of fruits and salad stuff and asked them to make some healthy sandwiches and snacks. The young carers also had the opportunity to try foods they had never eaten before – such as couscous. One or two people liked the couscous, but one young carer described it as 'tasting like dust'! While we were preparing the food, there was an opportunity to talk about kitchen hygiene, safety in the kitchen and healthy eating.



A second session was held in Berwick in December. This time there was a Christmas theme – making santa and reindeer fruit skewers.



Young carers at Cramlington Voluntary Youth Project (CVYP) took part in a cooking session in November. A selection of chicken, peppers, mushrooms, onions, peas and sweetcorn were stir fried with spices and herbs and then served with rice. The young carers were able to combine the ingredients they liked to create their own individual dish.

The young carers thoroughly enjoyed the session.

The final session took place in January, when young carers at Cramlington cooked pasta – with a variety of different vegetables. Prior to the sessions taking place, support workers had identified that some young carers lacked basic skills in the kitchen. One young person did not know how to dilute fruit squash. Support workers highlighted the benefits of the project and said they planned to continue cooking regularly with the young carers after the project had finished.

All the young carers were given a folder with recipe cards, kitchen hygiene information, an Eatwell Guide, and some fun worksheets to fill in. Recipes can be added to the files and young carers have written down some of the things they have learned, including a 'Top Tips' sheet.

Young carers at Berwick chose washing hands and using safety knives as their top tips. At a subsequent young carer support group, one young person cooked an apple crumble.



The Food Factor - Mini Food Festival

The project culminated in a mini food festival planned and organised with help from the young carers, which took place at [Cramlington Voluntary Youth Project](#) on Saturday 3rd February 2018.



Mini Food Festival

Date: Saturday 3rd Feb 2018
Time: 10.30-12.00
Venue: Cramlington Voluntary Youth Project,
Middle Farm Buildings, Station Lane,
Cramlington, Northumberland NE23 1DN

Come and hear from the young people and young carer support workers about the food factor project, as young carers share their views about health and support services in Northumberland .

Stalls will be available with, cookery demonstrations, tasters and freebies...

Every guest will be entered into a free prize draw with amazing things to be won!



The young carers from both groups were actively involved in planning the food festival – they agreed who would speak at the event, looked at plan of the building at Cramlington to decide where stalls and activities etc would be. They discussed what cooked snacks they would prepare, who would help with the raffle, in the kitchen, and discussed advertising the event via posters and social media platforms.

Some of the young people arrived early to help set up the venue and to begin preparing the food. Information stalls were provided by ourselves at Voices Northumberland, Carers Northumberland, North East Organic Growers, The CO-OP, Health trainers from Northumbria Healthcare and a self employed baker gave a cake decoration demonstration. Metro Radio provided a PA system which allowed us to have microphones and music throughout the morning. A number of people and organisations donated raffle prizes. Young carers and support workers cooked food to serve to the guests.



Young carers and some family members from Berwick travelled to Cramlington by bus to attend and participate in the festival. The young people actively engaged throughout the morning, signing in guests at the registration desk, organising the raffle, attending stalls or sitting down at the tables for a drink and chat. On the tables were pieces of paper which each had a quote from a young carer written on it – these quotes illustrated some of the issues raised by young carers during the project and were designed to provoke some discussions.



The Young carers had an opportunity to ice cakes with emojis to decorate the cakes with, and they were able to take home the cakes they had iced.

The CO-OP gave out a bag of healthy food to all the young carers. They said they were delighted for the opportunity to support the event and would like to support other projects involving young carers in the future. The North East Organic Growers fresh produce was divided up and given to families at the end of the day.

Guests helped themselves to some chicken noodle soup prepared by support workers and young carers in the kitchen.



Around fifty people attended the event.

The health trainers had brought some interesting 'props' to show the damage which can be caused to our bodies through an unhealthy lifestyle – many of us were shocked to see what a liver looked like after excessive alcohol consumption, and the realistic looking lumps of fat which showed us what causes weight gain.



It was an opportunity for young people and their families to ask questions, and get advice on a number of health issues.



The young carers had an opportunity to try out archery, in an adjoining room throughout the morning, and they were also able to play games of pool in the main hall.



There were some short talks about the project by staff from Voices Northumberland, CVYP and the young carers themselves. It was fantastic to hear the views of the young people who had taken part.



The project had not only given young people the opportunity to learn more about healthy eating, but had been a way to bring together the two groups from Berwick and Cramlington who had previously never met. Support workers and the young carers themselves were very positive about this experience and talked about how they could get together again in the future.

The festival came to an end at 12 noon, with certificates of participation handed out.



Part 2: Listening to Young Carers Voices

The four case studies outlined below, illustrate the high levels of care and support which young people often provide to family members. This can include personal care, housework, emotional support and caring for siblings.

It can impact on school attendance and school work and often causes young people anxiety.



Young carers often felt they were taking on a very adult role and the label 'young' sometimes seemed inappropriate to them. They often worried about the future and how their families would manage if they left home to go to university or to start work. This made them feel guilty that their families might struggle to cope.

Young people accessed support from local social services family units, schools and carer support groups. Both the support groups at Berwick and Cramlington were praised highly by the young people – they offered continuity and consistency of support, often over many years.

Part 2.1: Case Studies

Case Studies – all names have been anonymised and some details changed in order to protect confidentiality. However, the facts remain as understood by the young people themselves.

We endeavoured to identify some hidden young carers in order to consult with them through one to one case study, this was not possible so we focused on young carers who had not previously been consulted as part of the VoiCeS consultations.

Case Study 1 January 2018 - Tania

Age – 9

Lives – North Northumberland

Tania lives with her mum, her mum's partner, and two brothers one K who is 8 and the other S who is 5. One brother has ADHD and autism. Tania changed school recently and is now at Middle school.

Her brother K sometimes 'kicks off' and 'sometimes he has a meltdown'. 'Sometimes S can be bad as well. He might come into my room'. One time S got something stuck in his ear! K goes to a special school on a Sunday. To calm her brothers down, Tania uses a 'quiet pitch voice', sits next to her brothers and hugs them. Sometimes she gets them something to eat and drink. 'I never stop eating at home – my favourite food is pizza'

K loves Pokemon so Tania makes sure he has that. If they are kicking off too much Tania goes into her room.

Tania also cares for her Mum. Sometimes Tania's mum 'gets ill a lot and lies on the couch'. When that happens, Tania gets her something to eat and drink and tells the boys to 'shh' if they are making too much noise. Sometimes Tania rubs her mum's head if she has a headache. If her mum's partner is not there, Tania helps out. She sometimes lays the table for tea.

Tania has been attending the young carers group for about 4 months. Sometimes she isn't able to come because her mum isn't well. Tania was very positive about coming to the group.

'I like all the people here because they are really positive and friendly. I like the colouring and the activities and the food'!

'I like sometimes being able to cook here. I'm doing a cookery club at school. I thought if I learned to cook, I could cook something here'

Tania says that 'being a young carer can be fun'

Case Study 2 - January 2018 - Tom

Age – 16

Lives – South Northumberland

Tom lives with his mum, step-dad - who he regards as his dad and his brother J who is 10. His mum works two days a week and the rest of the time is full time carer for J. His step-dad works full time. J has considerable additional needs – ADHD, autism, LD, possible Tourette's, and is in remission from leukaemia. He has very little verbal communication, doesn't socialise easily - he attends a Church of England special school.

He 'kicks off' everyday by throwing trains, screaming, refusing to move, making a lot of noise. Sometimes you 'just have to leave him to it' in order for him to calm down. He used to wake up Tom very early in the morning, but he is better now – he has his I pads and watches Thomas the Tank engine, with which he is obsessed! Sometimes it was hard for Tom to leave the house when he was in school years 3-6, because J would kick off if he saw him leaving the house. Tom had to sneak out when J wasn't looking, otherwise J would cry until Tom got back home again. J had to know that Tom was in the house after school or he would kick off. He is ok about Tom going to school now and he also know that Tom goes to the young carers group.

Tom used to find J a bit embarrassing when they lived in a terraced house as J would wake up so early – the neighbours used to say that they used J as an alarm clock. He had to warn his friends about J's behavioural issues the first time that they came over for a sleep over. One time 'J stuck a pin in a friend's leg'! One woman in a shop 'had the audacity to say – can you not control that child. This made Tom feel really angry and a bit embarrassed too'. Tom thinks that there should be more awareness raising on issues about disability. He says that Sheldon in the Big Bang Theory and a documentary called the A word have been really useful in making people more aware of and have better understanding of what it means to be autistic.

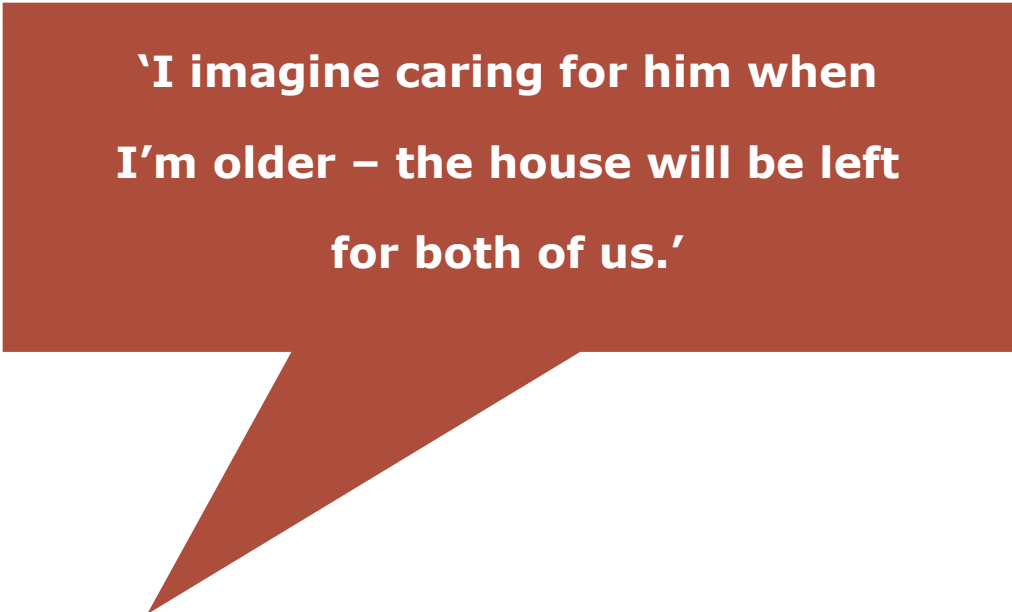
Tom's house is much bigger now and there is more space for J. Tom has his own room, which he can use if he needs some space to himself. There is a hot tub in the garden which J loves, and he also has a sensory room. Tom takes J to the sensory room, the hot tub or gets his iPad ready to calm him down if he is 'kicking off'. His Dad has a pass, which means he can take J for free to the trampolines, riding or swimming. Sometimes Tom takes J outside to play with his Segway go-cart.

Tom's mum and dad don't really get a lot of breaks. Their grandparents babysit about twice a year to let them go out. J is very good with his grandparents!

Tom is currently at High School. He cannot wait to leave as he is not enjoying school. He said his school had previously been in special measures. Tom plans to leave in the summer. He is hoping to do an apprenticeship in carpentry and joinery with a private firm or with the council. He also has a backup plan which is a place at Newcastle college to do carpentry and joinery.

When Tom was in primary school there was a young carers group which he attended for support – which he liked. In year 9 a new teacher started a group, but never carried it on. Lately, there has been no specific young carer support, but Tom's construction teacher has been supportive – he understands that Tom cannot stay late sometimes because of his caring responsibilities.

Tom has given a lot of thought to his future – and he is very clear that J will continue to be a big part of his life. Tom looks forward to getting his own place when he is older – and J will come and sleep over every Friday night. If he becomes a millionaire, he will have a butler to help out with J!! There is never a dull moment in the house with J there – everybody loves him!



**'I imagine caring for him when
I'm older – the house will be left
for both of us.'**

Case Study 3 – February 2018 Rachel

Lives - South Northumberland

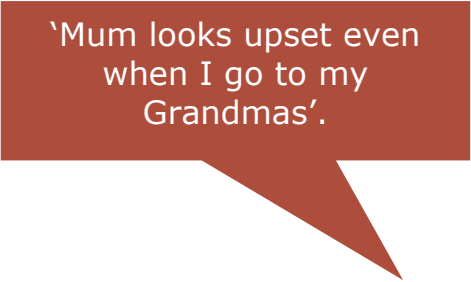
Age – 14

Rachel lives with her mum, who has various health issues, a sister aged 7 who has ADHD, a brother aged 9 who has emotional, anxiety and anger issues. Rachel's older brother is autistic and is at university. Sometimes Rachel has found herself caring for all 3 siblings. Rachel's Grandma, with whom she stays 2 nights a week has depression, arthritis and had a mini stroke a few years ago. Rachel's uncle is bi-polar.

On a day to day basis Rachel provides high levels of care. She gets breakfast for her siblings, dresses them, she baths her mum (the family are getting a walk-in wet room fitted as Rachel struggles to lift her mum out of the bath). Rachel does a lot of the housework too – cleaning up and doing the dishes. There is support going into the house from family recovery – who offer talking/support. Rachel shares a bedroom with her sister. Her sister regularly puts disco lights on at night and this is affecting Rachel's sleep. Her sleep is also disrupted because she feels stressed and worried. Rachel says her older brother sometimes used to hurt her mum. If Rachel was feeling stressed, she would go outside to see her two guinea pigs and rabbit, to get some space. Rachel used to have a dog, but one day she came home and the dog was gone.

Rachel feels that support from the school has been inadequate 'the school pretend they don't know I'm a young carer'. 'I used to have a school nurse. They said they would bring someone else, but they never have'. The pastoral care at school mainly focuses on bullying. 'My school is very strict. The school rang my mum and expected me to be in even if I'm ill, and threaten to come and get me from the house'. The schools don't seem to understand the twin pressures that young carers are under. Rachel says that she doesn't open up to many people any more 'My best friend knows all about it, but that's about it. I don't trust other people' 'I don't turn to anyone anymore' She does however feel able to talk to the support workers at the young carers group. 'They listen to us and offer help to get through things'

Looking to the future, Rachel says she would like to be a vet, but worries her grades won't be good enough. She feels the school are pushing her to be a nurse. Rachel feels guilty when she thinks about possibly leaving to do something in the future.



'Mum looks upset even when I go to my Grandmas'.

Rachel thinks some weekends away and a proper break would be good. Rachel finds the term young carer difficult – but it is hard to find an alternative.

Case Study 4 – February 2018 Melissa

Age – 16

Lives – South Northumberland

Melissa lives with her mum who has depression and is a full time carer for her brother D. D is 22 and has cerebral palsy.

Melissa gives D his medication and makes his breakfast. D now has support coming in daily from a local support organisation. They come in twice a day for approx. 30 to 45 mins to help D shower and get dressed/undressed. They have been coming for about 3 years. This has been much better for D as a male carer is more appropriate for a man of his age.

D can get frustrated and lash out a lot. Sometimes he hits Melissa's mum and her mum has to go to her room to get out of the way. Melissa uses different techniques to help calm him now. Sometimes she uses music and sometimes she just sits and talks with him. 'The dog is therapy for D'. Sometimes D goes to the a special centre locally to give her mum a break. Apart from that, there is not really any other family support.

Melissa goes to her own room to get some space. Melissa says she is used to not having much help 'I don't really turn to anyone'. The school set up a Young Carer group about a year ago – the support worker there just didn't understand the issues Melissa faced. It came to a stop a while ago. Melissa says the 'my best friend is really good' and if she needs to speak to anyone else, she will speak to Claire at CVYP because 'she understands'.

Melissa feels that she has been put under pressure from the school to attend revision classes after the school day has finished. She cannot always attend these because of her caring responsibilities. She feels that there has been 'not much help to manage the workload of exams revision'.

Looking to the future, Melissa worries about leaving home to go off to university. She described feeling guilty about the idea, but thought that D would accept new carers, if he got to know them well. Melissa would like to study criminology at either Durham or Leeds.

Melissa also thought that the term young carer was problematic, but wasn't sure what other term could be used.

2.2: Consultations with Young Carers

October 2017 to March 2018

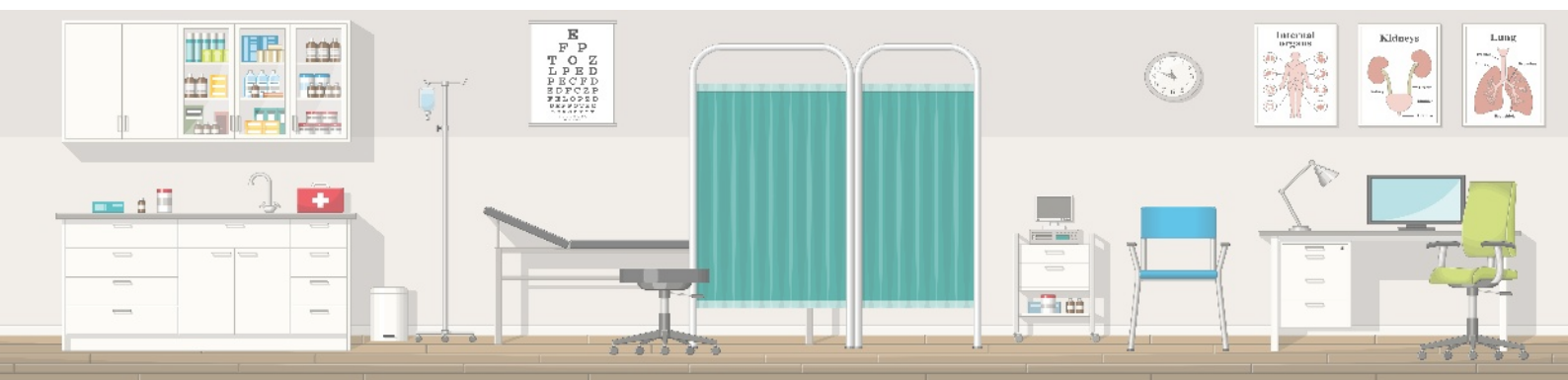
We spoke to 17 young carers, 2 volunteers and 3 support workers at Cramlington, and 8 young carers and 2 support workers at Berwick over a series of discussion groups between October and March. The age range of the young carers at Cramlington was 11-17, with the average age being 14, the age range at Berwick was 9-15, with the average age being 12.

There was a mix of young carers who supported siblings, parents, grandparents and step family members, who had a range of additional needs including mental health, ADHD, ASD, Cerebral Palsy, learning difficulties, were terminally ill, and physical disability. Most families had support from social services, some had paid support coming into the family home. Young carers helped provide support with a range of activities in the home including housework, cooking and meal preparation, gave personal care, looked after siblings and sometimes helped with medication or procedures such as changing peg feeds. We spoke to carers about a number of key areas associated with their physical and mental health well-being. We also talked to them about their experiences caring and living in Northumberland and their support networks.

Health and Well-being

GP Surgeries

Several issues were raised by young carers, support workers and volunteers regarding GP services both in the north and south of the county. Making/getting an appointment was the biggest problem faced by those we consulted. More than half of the people we consulted commented on the difficulty in making an appointment, the problem with the phone back service Doctor First, the lack of things to do in waiting rooms and the confusion over where to go in the event of a medical problem. A few surgeries were praised for ease of making appointments. Support workers queried whether priority was given to carers when they telephoned - ie was being a young carer being flagged up to receptionists and nurses. They also questioned whether young carers were able to speak on someone's behalf if required. One support worker had concerns that the multiple places offering a medical service could be confusing for young carers.



This is what young carers and support workers told us:

'Getting an appointment is murder. The GP assesses over the phone – it's very inconvenient, not very practical. My mum hates it she just doesn't go to the GP anymore – it's too much hassle to go to the GP, so we end up in the walk in instead'

'The GP has got worse over the years. Access to the surgery is difficult. My grandad had a two week wait for a GP'

'There are only a few time slots to attend - sometimes my brother has missed an appointment'



Support workers outlined issues they, or parents, had told them they had experienced with GP services including the introduction of the phone back system Doctor First. They talked about a reluctance to phone GP's because they thought it would be too difficult to get an appointment. Advice was often sought from pharmacists rather than GP's. There were difficulties with systems at other surgeries too, with people queuing to get appointments. One person was told it would be 7 weeks to register at a surgery.

'One surgery does Doctor first one doesn't – my surgery is still good but the other one isn't'

'I don't bother, because it is too hard to get an appointment'

'Some people have to queue to get early appointments, others have to phone and be triaged. There are time constraints on GP's – they don't have enough time'

'I can't always see the same GP, which means lack of continuity of care'

'I have heard of people using A&E because they can't get a GP appointment'

'Being able to see the same GP? - that would never happen'



'I was only able to get an appointment with a nurse practitioner.'

The receptionist could be a barrier/problem for some. Although they were aware that they could refuse to tell the receptionist what is wrong, in practice, people felt pressured to do so. Some found this embarrassing, especially if they found themselves having to talk in front of other people. One person described being 'diagnosed over the phone' via a phone consultation

***'It is sad and
frustrating that our GP service
is not so good'***

***'I don't like having to tell the
receptionist what is wrong – you
feel pressure, even if you don't
have to'.***

***'It was awkward
getting the phone back - I
was in Blackpool!'***

Some said they experienced long waits at the surgery – this could be difficult if they had a sibling with additional needs with them. A number of surgeries provided no, or very few, toys, books or things for older children to do in the waiting room. One young carer described being ‘stared at’ as a family, if their sibling was ‘kicking off’ because they were bored waiting. The youngest young carers were less aware of GP services generally, but did comment on the lack of things to do in the waiting rooms and suggested more books and an iPad would be good. ‘The RVI has an x box’.

‘There are no toys anymore for children to play with while they are waiting’

‘There’s only a little play bit, it’s terrible’

‘If the surgery had an iPad and toys to play with that would be great’

‘Lots of waiting and nothing to do’.

Many young carers, volunteers and support workers had problems with the multiple places they might be expected to attend – pharmacy, walk-in, surgery, Cramlington, Wansbeck or North Tyneside.

‘There is a list in the GP telling you where to go – it is confusing, it is back to 24hr at Wansbeck, sometimes it’s Cramlington, or you can go to the walk in at Wallsend. I heard of a woman from Germany who was really confused and didn’t know who or what number to call’

‘At night there is a different number to phone, there is a website for on-line appts’

‘There are too many messages/options on the GP answerphone. It takes ages to get through’

‘My grandad was given the wrong prescription at the pharmacist – mistakes happen’

‘My gran had had a stroke, the receptionist asked questions about the tablets and my gran said ‘why do you have to know’?

There were some surgeries which were praised for providing a good service. Some young carers felt their GP was kind 'my doctor listened - she was nice'. One GP surgery was praised for same day appointments and toys available in the waiting room. One support worker said she usually managed to get an appointment for her daughter, but she thought it depended on who you asked or that the situation might be different if you were an adult or a child'.

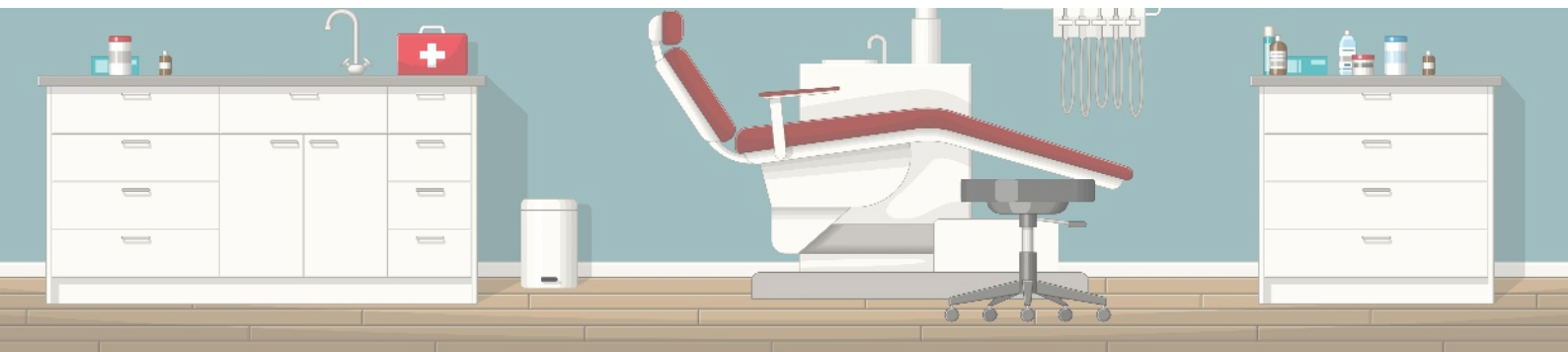
'My Gran uses the local surgery, if you ring early, you'll get an appointment'

'The Doctor was nice'

**'They do listen.
Sometimes it's trial and error with my meds for eczema'**

Dental Surgeries

The overall comments regarding dental services were positive across both groups – most saying the advice they got was good. Most young carers attended dental check-ups on a regular basis. Only a couple of young carers had had a filling. One young carer had had two teeth out, another had had 4 teeth extracted - they said they had forgotten to brush their teeth on a regular basis. One said their parent had only 4 teeth left. One young carer said they were going to need an operation when they were older. Only one young carer said they hated going to the dentist. Most brushed their teeth regularly with about half using normal brushes and half using electric. Most carers knew about plaque build-up and what caused tooth decay and they were aware of the dangers of sweets and fizzy drinks causing fillings. Eight young carers said they went for 6 monthly check ups, two said they went 3 monthly, one went once a month to the dental hospital, one attended yearly, and the rest were not sure. Four young carers either had or were getting braces. Most said didn't mind going to the dentist. One young carer didn't like her teeth being painted as it tasted 'disgusting'. Some young carers brushed their teeth twice a day, one said at the weekends and another twice a week. Younger carers said they sometimes needed reminding to brush their teeth. Occasionally young carers had been told by their dentist that they weren't brushing enough. Most went to a dentist locally and a few attended the dental hospital in Newcastle. Support workers commented that guidelines for brushing before and after meals and how often you should brush your teeth changed quite frequently, and said they would appreciate some up to date guidelines.



The young carers told us the following:

'Sometimes it is difficult to get there as there is no bus, so I have to get dad or grandad to take me'

'I have 6 monthly checks and I go to dental hospital too'

'The dentist is lovely there are no problems getting appointments'

'The dentist in Ashington is good, I have braces and checks on a regular basis'.

Alcohol Rise Above Programme

'Rise Above for Schools from Public Health England provides free PSHE resources that support secondary school teachers when promoting positive health, wellbeing and resilience among young people aged 11 to 16' (Rise Above, 2017).

We asked the older young carers whether they had heard of the Rise Above programme. We also asked them about information on drugs and alcohol, where or who they went to for advice, and their knowledge of the issue locally. Only one volunteer had heard of the Rise Above programme, but they did not know what it was and no young carers had heard of it. Most young carers at Cramlington said they would prefer to speak to someone at CVYP about drugs and alcohol or relationship issues. Some young carers said they would use the internet to find information on drugs and alcohol. Young carers thought advertisements for alcohol were ubiquitous at Christmas 'they are part of every Christmas meal'. They also thought that Christmas advertisements promoted alcohol encouraging people to buy it cheaply in bulk.

Well-being days at school were described by most of the older group as 'a nightmare'. The format was considered wrong, and needed to be more realistic, 'we're more street-wise than the teachers'. Young carers thought it would be better to talk to people who had experienced issues around drugs and alcohol. The PHSE or well-being sessions at school were also called 'boring' – 'we have done loads on bullying and then it's make a poster and go home'.

One or two young carers thought that school could be a good setting for 'PHSE stuff' but that sometimes smaller groups might be better and splitting into boys and girls for some sessions. One volunteer goes to Ashington college. He has had a tutorial there about drugs and alcohol. He thinks it is a real problem in Ashington because of high unemployment, and people spending money on tabs and drink. He says he is 'the only one in Ashington who doesn't smoke or drink.' He had heard of Rise Above but didn't know what it was about. 'Blyth isn't good. It feels like there is danger around'. Drugs and Alcohol were also considered an issue in Ashington 'One pill can kill you'

Young carers told us:

'We get mixed messages about alcohol – it's bad for you but it is promoted everywhere'

'The adverts make alcohol look good. There are gambling adverts too'

'I can't be bothered to read information on drugs'

'It's easy to drink and share pictures on snapchat'

'Our age group drinks quite a lot'

CVYP – 'it feels more confidential here, than it would be at school'

'They talked for 3 hours about hate crime at school it was too much.'

Emotional Well Being/Northumberland

Almost all the young carers talked about needing time to themselves and how important it was to them. They did a number of activities when they were on their own – watch anime, go on their phone, play on their play station, bake cakes and tray bakes, go to the beach for a walk, go to their room or watch TV. Both groups enjoyed meeting each other at the Food Factor and suggested some more joint events would offer opportunities of mutual support.

Transport was a concern in Berwick as there are no longer any buses running after 5.30pm. One carer now has to get a taxi home when they attend a youth group in the evening.

One support worker had concerns regarding issues with Early Help Assessments (EHA's). There was a problem with the referral system and sometimes the paperwork was not being completed on time. This had led to potential worries about funding – ie would YCs funding for their placements at CVYP be met if paperwork was not completed.

What is an Early Help Assessment (EHA) and how can it help me?

An **Early Help Assessment (EHA)** involves listening to you and your family to find out what you need and what is working well in your family.

The EHA will ensure that everyone involved works together to get the right support for you and your family...

To find out more about an EHA contact:
Anthony McArdle - North and Central **07717 816712**
Anthony.McArdle@northumberland.gov.uk
Emma Foote - South East and West **07767 788833**
Emma.foote@northumberland.gov.uk

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All young carers involved in the project had an EHA, or had a social worker, but support workers were unsure if young carers were being seen on their own or only as part of the family during the assessment. All carers were given a card in their food factor folders about early help assessments - pictured. Support workers at Cramlington were concerned about the time delay in processing referrals and therefore funding. They also expressed worries that one or two families would not want the young person to attend if they were asked to get an EHA done. For example, they had one ex carer who might not meet criteria (the person they had cared for had died) or another young carer being looked after by grandparents.

One young carer had had experience of the crisis team – they came too late to save his Dad. He used to go to Barnardos, now he gets help from a Children & Young Peoples Service (CYPS) counsellor. His friend has also lost a parent who took their own life, so they support each other. He is technically no longer a young carer as his Dad has died . CVYP have him down as a volunteer in order that he can remain with the group. Support workers talked about the importance of continuity and what provision there is for young carers who might experience loss?

Three young carers talked of the negative comments they or their family heard especially when the sibling they cared for had additional needs.

Support from their young carer groups was very important to them – other young carers understood because they had had similar experiences.

**'Young carer
looks good on
my CV'!!**

**'Older people say things about my
brother like "they wouldn't behave
like that in my days"'**

**'A passer-by said to me "he looks
dead" about my brother'**

**'I don't like to talk about
caring - I don't want
to be a burden.'**

Emotional Well-being - Support for Young Carers at Schools and Colleges

We were informed of, real problems at one High School which has had negative press reports locally. This has resulted in some parents considering sending children to a different school instead. Support workers were worried that young carers would find that some of their friends were going a different school, or they have to go to an alternative one, and they might lose some of their support network as a result.

The 3-tier system was seen to offer good support in the early years – there is a support group at First School and a pastoral support worker at middle school – but support appeared to tail off at High School level. Some young carers had support from social workers from Children and Young People Services (CYPS).

One young carer who goes to a special school, said the support is good and they can talk to anyone. A local college had offered very good emotional support to one young carer 'they are there for me 24/7'

'There is good support at college – care support officer, advice is available'.

'I don't have support at home'

'I get good support from Cramlington Voluntary Youth Project'



What's it like living in Northumberland - Keeping Active, Being Part of the Community

We asked young carers what it was like to live in Northumberland, the things that they did, the places they went to and any problems or difficulties they encountered in their day to day life. Young carers took part in a number of physical activities including netball, riding bikes, football, riding scooters, swimming, dog walking, Tae Kwondo and swimming pool discos. Currently swimming sessions are being funded by the young carers group at Berwick. A number of the older young carers felt that local supermarkets and shops targeted teenagers all the time – 'like McDonald's, we get kicked out, we get stereotyped all the time. It's discrimination' 'we get followed by security around the supermarkets. You can see them looking – it's kind of creepy - sometimes we move things in the racks to wind them up'. The beach at Blyth was considered good, but there were problems in Blyth too. Young carers talked about high levels of drug taking, people throwing fireworks. Some young carers felt embarrassed by graffiti which they saw locally - particularly at the skate park.

There was lots to do in North Northumberland but it was considered very expensive – places discussed included Alnwick garden, Seahouses, Paxton House and watching Berwick Rangers. Toilet provision was highlighted as poor in Berwick – with some parents taking a potty with them because they couldn't find a toilet for their child to use. A number of places have signs up saying you have to buy something to use the toilet and one cafe charged a £1 to use their toilet.

The young carers told us the following:

'There's nowhere to go, we can't really stay out'

'Things are too expensive'

'I go dancing and boxing'

'I have a pass for the cinema'

'People are friendly and nice, there are lots of opportunities'

'Things to do in Northumberland can be quite expensive, but my mum now has a card which means her carer can go free, and that has really helped'.

'I sometimes play badminton or tennis'

'Swimming is cheaper than other activities'

'Bowling, clip and climb, roller disco, and air box are good but expensive'

'There is not a lot for teenagers or older young people' 'there's nothing to do, it's cloudy and rainy and not much sun'

'There are sports classes, but these are better for older people or if accompanied by an adult'

'There's not much to do in Ashington – sometimes I go to KFC'

What would Young Carers like to see in Northumberland?

The young people who took part in the discussions had plenty ideas of places and activities which they felt would improve the places they lived, and make a difference to their lives, these included the following:



2.3: Raising Awareness - Social Media Campaign

'Many young carers remain hidden from official sight for a host of reasons, including family loyalty, stigma, bullying, not knowing where to go for support. Some young carers are as young as five years old'. (The Children's Society, 2013)

VoiCeS Northumberland facilitated a project with young carers to develop a social media campaign. A professional photographer was engaged to work with the young carers over a six month period. The aim of the project was to produce a media campaign to raise awareness of the roles and lives of young carers and some of the issues they face, particularly those young people who undertake a caring role, who have not identified themselves as carers.

The project planned to work with a minimum of 10 young carers to gather opinions, information and quotes and co-produce appropriate visual resources and photographs to use within the designs. Young carers attended a number of focus groups to talk about their caring roles and worked with the photographer to on a series of photos on subjects relevant to their lives. Click [here](#) to read the summary.

The photographer produced a series of images and designs and young carers were actively engaged in co-producing the finished materials. The project produced:

- 3 poster designs: 2 targeting young people over 11 years old and one targeting the wider community including schools and service providers.
- 26 designs for use within an online awareness raising media campaign, with implementation of a 6 month social media campaign from May 2018.

Young carers were actively engaged in co-producing the finished material by offering constructive criticisms and comments including final choice of designs. A number of staff and volunteers from the young carers support groups also provided feedback on the draft designs.



Young carers at Berwick were able to articulate very clearly which draft designs they liked best and why. They paid attention to details such as background colours, font size, clarity of words, number of words and headings. They also articulated why some photos provided more accurate representations than others. For example, a picture of two people holding hands they thought evoked 'friendship' rather than 'caring'. They liked the anonymity of some of the pictures by not showing the person's face – see pictures. Too many words, some pictures like the drums and the snooker ball pictures too fussy or didn't tell a story etc.

With feedback from young carers the collection of 45 designs were revisited with 30 designed being chosen for use in the final social media campaign.

Photo based designs and cartoon characters were created to be used in paired designs: Yellow designs targeted young carers providing a positive message about their experience and blue designs targeting and adult audience and providing messages about less positive experiences.

The final designs were tested on several platforms including Facebook, twitter and Instagram.



I'M A YOUNG CARER
I help look after my dad.

If you are a young carer who helps to look after one of your family, you can get help and support by contacting
 VoiCeS Northumberland
 on 01665 713109
 or contact@voices-northumberland.org.uk

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WE ARE YOUNG CARERS
We need support

If you know a young carer who helps to look after someone, you can find out what help and support is available by contacting VoiCeS Northumberland on 01665 713109
 or contact@voices-northumberland.org.uk

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Part 3.1: What did young people tell us?

Overall, the young carers and support workers were positive about the food factor project and wanted to continue to have opportunities to cook and prepare meals.

Many of the young carers helped their families at home, and they believed an awareness of kitchen safety, hygiene and basic meal preparation would enable them to do so with more confidence.

Some young carers were providing high levels of support at home including personal care.

Young carers, families and support workers reported difficulties in getting GP appointments. Knowing who to contact first in the event of a medical problem caused confusion for some people. There was often little for young people to do whilst waiting in surgeries.

Dental services were generally considered to be good, but it was suggested some up-to-date oral health guidelines might be helpful.

Young carers appeared to experience good pastoral support at school in their early years, but secondary school support was not always as good. Young carers expressed a preference to talk to support workers at support groups than school teachers – although some individual teachers clearly showed good understanding of individual children's needs.

Young carers did not think the information they received from schools about drugs and alcohol was relevant. They felt they knew more about the subject than many teachers. PHSE lessons at school were often described as 'boring' or irrelevant.

Young carers experienced high levels of guilt when contemplating leaving home in the future.

There were some activities and places in Northumberland which young carers enjoyed taking part in or visiting. Many activities were considered prohibitively expensive and accessing transport could sometimes be problematic.

Young carer support groups were very important to the young carers. Peer support and friendship and empathetic staff provided them with a space which was different to school, and offered opportunities to talk through issues in a place where they felt comfortable.

Having some time to themselves is important to young carers – and they don't always want to talk about their caring role.

3.2: Food for Thought: What Needs to Happen Next

A number of young carers were providing support to a terminally ill sibling. One young person was no longer caring for a parent because they had died. This raised questions about the need for flexibility in the funding system to allow young carers to continue to receive support from young carers groups (if that is their choice) when their caring role ends and they are no longer entitled to an Early help assessment (EHA) as a young carer.

Support Workers raised concerns about the time it was taking to confirm funding for support activities once a EHA was complete.

The nature of the assessment (EHA) was questioned in terms of whether young carers are consistently being offered an opportunity to speak on their own or are only consulted within the family assessment.

Young carers are experiencing difficulties meeting the expectations from school, whilst maintaining their caring and support at home. This can be particularly problematic during exam and time, when extra classes after school are being offered for revision. Develop a training package raising awareness of young carer issues to be delivered as part of the Early Help Training Programme. In addition co producing a school assembly for key stage 3 telling a young carers story and outlining support available.

Rolling out a social media campaign to offer to GP practices and schools on information screens.

Young carers are aware of drug and alcohol problems in their neighbourhoods. However, there appears to be a lack of up-to-date information available for young people and further, young carers struggle to engage with the topic during PHSE lessons at school. Would an information course developed and delivered at the young carers support groups engage young people more effectively?



Young carers experience a number of problems with access to Primary Health Care and there is some confusion apparent regarding the multiple places for contact in the event of them requiring medical assistance. This raised questions as to whether, or not, young carers are flagged as needing additional assistance during the triage process and whether the current information available to support navigating the system meets the needs of young carers. Does an easy to understand guide for young people exist or is this something that should be considered.

Transport availability and costs can be prohibitive for young carers. A particular issue was raised in the Berwick area, but how do we ensure that young carers are not missing out on extra-curricular activities.

Both support groups would like to have further opportunities for join activities in order to maintain the link they have established, develop their services, share knowledge, good practice and issues that affect both groups.

Further cookery classes, would offer young carers a chance to develop their skills further and offer opportunities to be more creative in the kitchen.

Issues around guilt featured in discussion in relation to young carers making choices for themselves and their future, particularly as they approached school leaving age. Material /forums suitable for young carers as they deal with these emotions and try to balance the often competing demands and needs could provide a valuable resource.



3.3: Acknowledgements

Thanks to all the young carers, volunteers and support workers at Berwick and Cramlington for the time they have given during the sessions. Thank you also to families for supporting the food festival, organisations who donated raffle prizes or who had a stall that day.

Carers Northumberland
Cramlington Voluntary Youth Project
Alnwick Playhouse
Grannies
Cramlington Co-op
North East Organic Growers
Metro Radio
Northumbria Healthcare
Gillian Mabbitt



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[Young Carer's Needs Assessment](#)

[Children's engagement with the outdoors and sports activities](#) UK: 2014 to 2015

Carers Trust - [Know your Rights](#)

Public Health - [Eatwell Guide](#)

Food Standards Agency [Kitchen Check](#)