Support for carers
Experiences of accessing support in North East Hampshire and Farnham

June 2016
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Introduction & context

Healthwatch is the independent consumer champion for health and social care in England. Healthwatch’s function is to engage with local people to seek views about locally delivered services, signpost service users to relevant information and to influence the design of local health and social care provision.

Healthwatch Hampshire is part of a network of local Healthwatch across 148 local authority areas that launched in April 2013 to ensure local voices are heard and enable them to influence the delivery and design of local services. Our sole purpose is to understand the needs, experiences and concerns of people who use health and social care and to speak out on their behalf. Healthwatch have statutory powers, as stated in the Health and Social Care Act 2012, to ensure the consumer’s voice is strengthened and heard by those who commission, deliver and regulate health and care services. Local Healthwatch helps people get the best out of their local health and social care services; whether it’s improving them today or helping to shape them for tomorrow.

The CCG Vanguard Programme, ‘Happy, Healthy, at Home’, is aspiring to drive a culture change across the system and put engagement and co-production at the centre of everything they do. This means that local people need to be actively participating in the design and delivery of services.

The Vanguard Prevention Workstream in partnership with Healthwatch Hampshire planned an initial ‘design group’ to bring together approximately 25 carers and organisational representatives on the 22nd January 2016. It was well attended and an initial report was created by Healthwatch Hampshire that presented feedback about current services as well as made recommendations for effective and positive engagement with carers in the future. An engagement plan was created and proposed by Healthwatch Hampshire and commissioned by North East Hampshire and Farnham CCG in March so that engagement work could take place in April and May. This final report summarises that engagement and makes recommendations about how to shape support services for carers in North East Hampshire and Farnham in the future.1

1 To read the initial report submitted to the North East Hampshire and Farnham CCG, please follow this online link to the Healthwatch Hampshire website where the report is accessible. http://www.healthwatchhampshire.co.uk/sites/default/files/carers_engagement_report_-_february_2016_1.pdf
Co-producing the project

Getting the engagement right and collaborating with key partners

One area that the design group focused on was how to best engage with carers about future support services. The carers and professionals that attended this engagement workshop recommended engaging with carers...

- at a range of times to accommodate different commitments
- at places where they are already attending a group or service
- at locations they feel comfortable and that have all the facilities they need (parking on site, disabled access and toilets etc.)
- and that they would like engagement to be paired with the opportunity to find out information and access support services

In response to this, Healthwatch Hampshire has engaged with over 70 carers from North East Hampshire and Farnham at Carers Hubs, Dementia and Alzheimer’s Society support groups, a young carers group and a Breathe Easy Support group. Healthwatch also set up a Nepali engagement group and presented to over 80 senior citizens.

Please see Appendix 1 for further information about the engagement events.²

Healthwatch Hampshire has worked closely with The Princess Royal Trust for Carers (PRTC), The Alzheimer’s Society, Citizens Advice, Rushmoor Healthy Living, Hart Voluntary Action, The British Lung Foundation and the local Senior Citizens Forum. The PRTC has been a key partner because they not only coordinate the local Carers Hubs where Healthwatch facilitated engagement activities but they have also attended carers groups alongside Healthwatch to offer support services to carers, providing information about setting up emergency plans, financial support for carers and to inform carers about local support networks.

² Healthwatch Hampshire also made contact (via the Culture, Communities and Business Services Development Dept, Community Support Team) with the Army Welfare Service, Naval Families Federation, RAF Families Federation, Army Families Federation and MOD/Aldershot Garrison to promote the engagement that would be taking place at the local Carers Hub, inviting Forces families to engage. (Poster/Invitation: Appendix 2)
Focus areas for engagement

The variety of groups and hubs that Healthwatch attended reached retired, full-time, working, parent and Nepali carers as well as young carers. Depending on the type of group, Healthwatch facilitated engagement workshops, group discussion and worked with carers on a one-to-one basis. The January design group enabled Healthwatch to establish five key areas to focus on during future engagement with adult carers. These topics included...

- How do you want to find out about carer’s support services?
- How could you be better supported with juggling your caring responsibilities?
- What support do you need to help you cope with the stress of caring?
- What kind of emotional support do you want and need most?
- What kind of practical support do you want and need most?

(See Appendix 3-7 for engagement activities and resources)

Professionals representing young carers at the design group in January also helped Healthwatch to define the engagement activities for young carers. The focus was on...

Creating the ideal support network for young carers

- Considering how they want to communicate with, be treated and supported by the medical professionals that they come in to contact with
- What advice would they give when looking at what services to fund in the future

(See Appendix 8-11 for engagement activities and resources)
The following feedback, experiences, ideas and recommendations are based on the engagement events facilitated by Healthwatch Hampshire with carers from North East Hampshire and Farnham.

Many carers said that finding out information about hospital discharge is difficult; For example, when discharge will actually be taking place, what care package will be in place when at home, how professional care will be paid for and who to contact for information, advice and support about this process.

Multiple carers discussed only being able to get information via the patient, which presents issues if they are elderly, having difficulty retaining information due to ill health or suffer from memory loss.

Carers also discussed not being included in hospital discharge plans and the care package not being suitable. Health and social care professionals often ask the patient about their capabilities when assessing their needs, but due to Dementia, Alzheimer’s Disease and personal pride, patients often say that they can wash, move around the house etc. without support, or say that their spouse, daughter or son can complete these tasks for them, when that isn’t the case due to their work or family commitments, difficulties with travel or their own physical health issues.

Carers reported that financial assessments for domiciliary care take to long and have been completed after hospital discharge and after a care package has been put in place. Two carers discussed receiving a bill after the financial assessment (£400 given as an example) that they couldn’t afford and were not expecting.

Carers caring for someone that lives on or near the border of Hampshire and Surrey said that it was very difficult to coordinate care after discharge from hospital in one area, but then needed the care package to be arranged in the other area. Carers discussed the financial strain, having to pick up the bill while financial issues were sorted out and complained about the time this took to organise.

Improving hospital discharge for carers, carers recommended...

- hospital professionals identify if there is an unpaid carer in the family and liaise with them
- carers having one clear point of contact at the hospital prior to discharge
- including carers in meetings relating to hospital discharge to ensure the patient and carer accurately represent the care needs
- a professional clearly communicates with the carer about when and how discharge will happen
- ensuring the carer understands the care package that will be put in place and the financial cost of this care package
Many of the issues facing carers that support someone living with Dementia or Alzheimer’s Disease are specific to these conditions, focusing on the diagnosis, hospital treatment, how the condition progresses and worsens and the type of care that they require. This section of the report focuses on the feedback and recommendations from the engagement events designed for these carers.

Please note that although the majority of carers were retired spouses that considered themselves full-time carers, Healthwatch also engaged with sons and daughters that were caring for one or both parents as well as managing part-time or full-time employment with dependent children living at home.

**Support groups**

Receiving help and support from other carers was really important to many of the carers that we engaged with. Being able to talk to other people “in the same boat” that “really understand Dementia and Alzheimer’s Disease” seemed to be the best type of emotional support for those that accessed it.

Many carers said that groups run by support workers that were “experts in their field” (e.g. Alzheimer’s Society) enabled them to get advice and guidance that hadn’t been available elsewhere from health or social care professionals.

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**Case Study**

“The initial mental health support from ACfH was really good but then after my Father was diagnosed, he was discharged by letter and we had no one to call that knew our situation. My Mother and I suddenly felt abandoned. We had no idea who we could call or what would happen next. We had this devastating diagnosis, medication was prescribed... and then discharged! Nothing about our wellbeing or his. My Father used to care for my Mother because she has COPD and physical disabilities but none of this was taken into consideration. After being discharged, we were told to make contact with the GP if my Father’s condition changed or worsened...that left us, the family, responsible for monitoring his deterioration and making decisions about what to do next and when. We felt very under-supported.”
Carers often discussed initially avoiding support groups soon after diagnosis because they were fearful of hearing “horror stories and being faced with what the future holds”, but said that knowing the professional that ran the group prior to attending made the initial visit easier.

Many carers said that transport and respite should be provided to enable carers to attend support groups so that they can receive the much needed emotional support from peers and professionals.

Groups that welcome both the carer and cared for were liked by some but not others. For these groups to be successful, carers said that activities for the cared for need to be well staffed and offer varied activities and that the carers need to be able to congregate in a separate space to enable them to speak candidly.

### Dementia and Alzheimer’s Disease pathway of support for carers

To reduce stress after a Dementia or Alzheimer’s diagnosis, carers recommended that they need help to order their priorities. With support from a wide range of carers, Healthwatch would recommend a ‘Dementia and Alzheimer’s Disease Pathway of Support for Carers’. Carers listed the following as essentials for this pathway:

- A face to face meeting at home with a specialist support worker from the Dementia Advice Service a couple of weeks after diagnosis to signpost, advise and listen to fears, concerns and answer questions.
- Applying for and support with Attendance Allowance because it can’t be back dated.
- Applying for and support with receiving reduced council tax (finances may help with care costs).
- Receiving an invitation to their local Carers Hub and being put in touch with local support networks.
- Putting an Emergency Plan in place.
- Receiving support to obtain Lasting Power of Attorney where necessary.
- Registering as a carer with the GP.
Project feedback

3. Parent carers

Some parent carers caring for disabled off-spring are full-time carers, others have work commitments as well as a family to manage. Parent carers discussed not managing their own health needs, feeling exhausted all the time and feeling as though they have to fight for support, whether that be at school, for respite or medical care. Parent carers with adult off-spring with learning disabilities also said that there is a real lack of day centre activities and work/community placements in the local area causing their caring commitments to be extensive and the cared for person lacking social interaction.

Recommendations from parent carers...

- Regular health checks to monitor their own health and wellbeing to ensure they are maintaining good health and are able to continue caring. Many parent carers discussed neglecting their own health.
- Respite to enable parents to focus on other children and their needs, to maintain a sense of their own identity and to access support networks. Schools, GPs and medical professionals, social services and Carers Hubs should refer families to...
young carers support groups as soon as they are identified

Community activities and work placements for disabled adults to provide respite for the family, to enable carers to work as well as reduce their stress because they know that their disabled child is doing something worthwhile that raises their self-esteem, health and wellbeing and provides much needed social interaction.

Emotional support and support returning to work when the cared for child transitions to residential care.

Case Study

“I cared for my disabled son from birth and was a full time carer for 19 years. When my son moved in to full-time residential care I felt completely lost. I was grieving for months and had no one to talk to. My whole identity had gone and was replaced with worry. We talk about the support that we need when we are caring but I desperately needed some help and support with the transition when the caring stopped.”

Project feedback

4. Emotional & practical support for carers

When discussing reducing stress for carers there were different types of support that they thought would be of benefit. Emotional support and practical support were key factors for all of the carers that Healthwatch engaged with.

In relation to emotional support, carers recommended...

- Having friends and networks of local people that are also carers to socialise with, share problems and get advice from

- Someone, whether that be a professional or peer group, to talk to about the medical condition before the condition deteriorates to help prepare them for the next phase

Support is needed to help carers to cope with anger, resentment and negative feelings towards the cared for person as well as the guilt of not being able care anymore and needing domiciliary care or a care home

There is a real need for professionals to be involved and familiar enough to spot when a carer is going to ‘hit crisis point’ so that they can put preventative support in place.
“Paid carers come in twice a day but the carers and the time they come varies so much that I have to be there too. The carer is supposed to come in the evening but can come anytime from 4-9pm. Whenever they arrive, they want to do Dad’s dinner and put him to bed, but that’s no good at 4pm! Also it means that his medication isn’t being taken at a consistent time so I have to do it.”

Dealing with house-related paperwork and the sale of property was discussed by multiple carers. Many felt very alone during this emotional time when a loved one has died or is moving to a hospice or residential care. Carers found it difficult to find any support during this time and said they needed to be signposted to Citizens Advice and other agencies that could support this process and advise them.

A professional to help family members have difficult conversations with the cared for person would be really beneficial. For example, giving up driving, not going out alone, having domiciliary care, moving in to a home etc. The carers discussed the benefit of separating themselves from those difficult and emotional discussions.

“My Mum hated me for trying to put her in a prison (care home). She couldn’t forgive me and the guilt I felt was just awful.”

Practical support with caring, such as help from care workers in the home or replacement care for the person they care for, is essential for many carers to be able to work alongside caring if they want to, juggle other family responsibilities such as childcare and to have a life of their own outside their caring role. Without this support, carers are often pushed to breaking point and have to give up work, stop caring, or even go into hospital themselves. Carers UK, State of Caring 2015 Report

In relation to practical support, carers recommended...

Continuity of paid-for carers in the home is essential. Many carers said that when paid-carers change too often, they were unable to leave the house because the cared for person was unsettled or their needs were not being met.
In relation to hospital appointments, if the cared for person is on a waiting list, the carer should receive a phone call during the interim waiting period to check how things are, if the condition has progressed and to provide an opportunity to share concerns and get advice.

A professional that ensures all carers complete a carers assessment and emergency plans. Generally carers wanted this practical support to be face to face and in their own home. Some carers shared experiences of completing forms ‘too optimistically’ (especially soon after diagnosis) and then not receiving the support they really need. If a professional were to assist carers to answer questions on forms and really focus on giving open and frank responses, it would ensure that carers are focused on their support needs as well as the cared for.

Carers said that subsidised transport for GP appointments and hospital appointments would really benefit them, especially when the cared for person is living in a very rural area without access to public transport services.

Many carers said that respite to enable them to exercise regularly would reduce their stress levels. They were keen to join walking groups, exercise classes, pilates and yoga classes as well as music and movement sessions to encourage relaxation.

"The Forget Me Not Café is a great place for carers and cared for people to socialise, relax and enjoy music together. I’m able to use flexi-time at work so take my father regularly but its not respite for me because you have to attend with the person you care for. There is definitely a need for more day centres and places for the cared for person to go to give the carer some time to be independent, even if it is just to do the shopping or the cleaning!"
Many people who carry out a caring role are elderly or have physical ailments that can fluctuate in severity. Many of the elderly spousal carers that we engaged with suffered themselves from chronic arthritis, COPD, high blood pressure and limited mobility. Reciprocal carers (two people caring for each other) discussed problems relating to both people’s care needs never being assessed by professionals at the same time. Carers said that when two people are looking after one another it is essential that they are assessed and reviewed together. They also said they needed practical coping strategies because he role of caring has a negative impact upon their individual health issues.

"My husband used to care for me because of my asthma, COPD and arthritis. He'd do the shopping and the driving and the housework but now he's been diagnosed with Dementia, I care for him. My needs have had to be put to one side. My son does what he can but he doesn't live with us and he works full time. No one has ever asked us how we manage really."

Working carers, that have a disability themselves but are caring for someone in the community (that they don’t live with) also discussed the emotional stress and exhaustion related to emergency call-outs in the middle of the night and the need for more out-of-hours support services.

“When I became a carer for my Mum and my brother, I needed help to understand the role I was undertaking. I didn’t know what a young carer was, I just did it for years.” Young Carer, 15 years old

Healthwatch Hampshire led an informal engagement workshop with a group of 11-16 year old young carers that regularly attend the Rushmoor and Hart Carers Group in Fleet, run by Hart Voluntary Action. 10 young carers engaged in the activities and shared their thoughts and experiences as well as their ideas about how services could be shaped in the future to better meet their needs.

Many of the young carers that attended the group are in regular contact with medical professionals, whether that be the GP, hospitals, A&E or ambulance staff, nurses and domiciliary care workers. The young carers were given a white medical coat and were asked to consider how they would like to be treated by medical staff in the future, based on their past experiences and to consider how this might better support them and other young carers in the future. The young carers wrote their ideas all over the coat and their feedback...
concluded that they would like medical staff to…

- Be more caring, understanding and kind
- Remember their age when giving complex or upsetting information
- Ask what they know and understand about the medical condition, so not to belittle them
- Not label them as angry teenagers from broken/troubled homes. Ask me what emotional support I need and if I am coping
- Be non-judgemental
- Not expect us to do adult caring duties but then treat us like children!

**Stress for young carers**

During an engagement activity about choosing which areas they needed support with most, the young carers said that support with stress was their primary concern. Stress relating to administering complex medication to a parent or sibling and the risk of getting it wrong, not understanding the dosage on the pack or not understanding verbal instructions. They also said that they felt stressed about their ability to cope with emergency situations (seizures, choking etc.) and not feeling well equipped with the necessary first aid knowledge, especially if they are in sole care of the cared for person.

“I administer medication but no one has ever explained to me what it’s for, what possible side effects might be or anything.”

Young Carer, 15 years old

“We should be offered first aid courses. When my brother had a seizure, I thought the worst and just didn’t know what to do. It was really scary.”

Young Carer 12 years old

All of the young carers also discussed stress related to juggling caring responsibilities and school work and there being a lack of understanding from teachers and their peers about the caring duties that they undertake and the impact that this can have.

“My Head of Year knows I’m a young carer and knows my situation but none of my class teachers seem to know anything. I don’t want to have to tell people over and over again, I’m happy for the Head of Year to share this information if it makes my life a bit easier.”

Young Carer, 12 years old

“Sometimes my caring duties stop me from being able to do my homework. I need to do the cleaning, the cooking and help look after my brother in the evenings but
teachers just don’t understand.” Young Carer, 13 years old

The group felt strongly that more needed to be done in school to raise awareness about young carers so there would be better emotional support and leniency where necessary in relation to completing high volumes of homework. They did however say that school peer mentoring schemes were not the answer for young carers because their peers don’t have the knowledge or experience to help them properly.

“General peer support networks and buddy schemes at school don’t work for young carers because these peers don’t understand the issues that we are having. Peer support groups with other carers are the best support for us.” Young Carer, 13 years old

“I want other children to understand what being a young carer really means so that they don’t bully us, especially at Secondary School.” Young Carer 13 years old

“There needs to be support workers in school that have first-hand experience of being a young carer when they were younger.” Young Carer, 15 years old

The young carers also said that they needed more respite from their caring responsibilities, that they sometimes feel isolated and that they think they should have regular GP appointments to check their own emotional wellbeing.

“Anxiety and worrying keeps me awake at night. Everything in my life has a time limit and there isn’t enough time to get everything done. I also worry that my brother might stop breathing at any time.” Young carer 14 years old

The ideal support network for young carers

Another engagement activity required the young carers to create the ideal support network for a young carer living in the local area. Using a large target and a fictional young carer placed at the centre, the group considered who they would place closest to them and worked outwards, creating a support network that would ensure the young carer felt supported.

At the centre of the target, the young carers placed family, the young carers group/network, a family support worker, support with stress and online chat rooms/forums to communicate with their friends from the carers group. These were considered to be essential.

Around the middle of the target, the group said that teachers and GPs were integral to supporting them emotionally and practically. They said that access to regular first aid courses, Makaton and handling courses would be really beneficial and more fun activities for young carers should be available, as well as the necessary transport, respite and financial support to enable them to attend. They said that they struggle to have hobbies like their peers, so the necessary transport, respite and

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1 Healthwatch Hampshire invited the parents (see letter, Appendix 12) of the young carers to get involved in this engagement project so that they would have the opportunity to advocate for their children and highlight support needs that perhaps the young carers hadn’t considered. Sadly no parents volunteered to get involved, but Healthwatch would recommend that this is pursued when future engagement with young carers is carried out.
financial support to enable them to attend a football club, drama group etc would make them feel less isolated and happier. They also said that counselling should be available if and when they need it without being placed on a long waiting list.

Around the outside of the target they said it would be good to have Information days at school, led by young carers to inform peers and staff about the role of young carers so that schools become more understanding and accepting environment for young carers. They also said that they would like access to medical specialists so that they are able to get clarification about the conditions that they are caring for, from people that understand how to communicate with young people.

To ensure that this engagement project reached young carers living in the Farnham area, Healthwatch Hampshire was keen to set up an engagement session in Farnham with a group run by Surrey Young Carers and Action for Carers. Unfortunately there were no events or groups running in April or May for young carers in this area. Farnham and Surrey young carers were however involved in two recent consultation events held by The Children’s Society and Surrey Young Carers. Please refer to the “Making It Real for Young Carers Report” that is intended to feed into the development of the new National Carers Strategy. The discussions focused on in this report included four themes...

- Making sure that young carers are identified, that their knowledge and skills are recognised and they are included appropriately in conversations or planning.
- Enabling young carers to fulfill their educational and employment potential.
- Making sure that young carers and their families get support that is designed around their personal needs, strengths and goals (personalised) so they can have a community and family life.
- Supporting young carers to remain physically and mentally well.

To ensure that young carers from Farnham were able to make contact with Healthwatch and get involved in this engagement project, Healthwatch Hampshire wrote a short article for the Surrey Young Carers Newsletter encouraging young carers in Farnham to have their say about support services in their area (Appendix 13). Also see a post-workshop response from Caroline Winchurch, CEO, Hart Voluntary Action (Appendix 14).
Project Feedback
7. Nepali carers

Healthwatch worked closely with Rushmoor Citizens Advice and Rushmoor Healthy Living to identify and invite Nepali carers to an engagement workshop in Aldershot to discuss the specific needs of Nepali carers living in the area (See invitation, Appendix 15). On the 26th May 2016 17 Nepali carers attended the engagement workshop and shared their experiences and ideas about how local support services could be improved to meet the needs of this community. Both Rushmoor CAB in Aldershot and Rushmoor Healthy Living helped to facilitate and translate the workshop to ensure it was completely inclusive of Nepali carers that do not speak English. Many of the Nepali carers have similar issues to other groups that have been engaged with, issues such as isolation, financial concerns and the need for respite or domiciliary care, but this section of the report will focus on making recommendations to overcome the specific issues that this community face when communicating with and accessing support services.

None of the carers that attended the workshop had ever heard of or attended a Carers Hub in the local area and no one was registered as a carer with their local GP. In relation to ensuring this community are well informed about support services they recommended...

Using existing, well attended groups such Nepalese Help (over 100 attendees regularly), health/support groups run by Rushmoor Healthy Living and Nepalese Drop-in services run by Rushmoor and Farnborough CAB to speak to the community. Translators and multilingual professionals attend most large meetings and would be able to support this information-giving. The group advised that word-of-mouth is a powerful tool within the community, so presenting a message to a large group will ensure the information is shared but that regular presentations would be necessary.

A quarterly newsletter in Nepalese for carers, that lists the current groups, support networks, contact details of support agencies and an insight into potential entitlements would help carers to make contact and start receiving the support that they need.
Promote support services and open up discussions and phone-ins about carers on BFBS Gurkha Radio. This could be an excellent way to address what ‘carer’ really means and help the community to understand the role and potential support that is available.

Avoid using the telephone to give information. Many of the Nepali carers that attended the workshop said that they struggled to understand information via phone. They recommended that GP surgeries should have one member of staff that can speak Nepalese so that when Nepali carers phone up or visit the surgery they can book appointments, get signposted to services and receive information about prescriptions and dosages.

Carers should be invited to English lessons because it is essential that they can communicate with the medical professionals that they are regularly in contact with.

English speaking members of the community should be able to attend an appointment with a non-English speaking member of the community (especially for routine/non-emergency appointments) and act as the translator. Many of the group discussed being turned away because they aren’t a professional interpreter or direct relative to the cared for person. Many of the carers said that they are often informed by GP surgeries and hospitals that translator services are not available, especially for emergency appointments.

The group said the community struggle to understand how to use the 111 service and 999 and that carers need extra support and training to help them to understand how and when to use these numbers. The professionals attending the session said that one-off workshops aren’t enough, that elderly carers especially, need regular reminder sessions.

A few carers discussed caring for people with mental health issues and how cultural differences and beliefs can prevent members of the Nepali community from accessing support or receiving more traditional medical treatment, preferring to seek spiritual healing instead. A few carers recommended that more information could be shared with the community about mental health to increase awareness.

Several members of the groups discussed issues relating to understanding prescriptions from the pharmacy so suggested a translation service to ensure they understand dosages, possible side-effects, what to do if medication is missed etc.
The majority of carers that Healthwatch engaged with were not registered at their GP’s surgery as a carer and didn’t know they should be, despite their GP often knowing that they are an unpaid carer. Therefore many of the carers that we engaged with did not receive any information about support from their GP.

Carers and cared for people also discussed the lack of referrals from medical professionals working in a specific areas and thought these professionals should know about and refer patients and their carers to local support groups.

“The COPD Respiratory Nurse waited 5 years to tell me about the local Breathe Easy support group. She had the leaflets, just didn’t think to give me one! When I finally attended the group, they put me in touch with a singing group which has improved my health and gives my wife some respite every week.”

Some of the older carers discussed finding information and support online very difficult. Getting lost in websites, not searching effectively, finding national rather than local information, not being able to download leaflets and not having smart phones to use the necessary apps. They discussed struggling to identify junk email and spam from useful emails and were worried about opening emails from unknown sources.

Some carers said that packs of leaflets about the medical condition paired with information about support would be most useful, although some professionals said that they often find families get overwhelmed (especially around the time of diagnosis) and tend not to process a large amount of information well.

Carers recommended...

- It should be targeted as soon as a carer is identified
- An invitation to their local Carers Hub should be issued
- This should be followed up by a support worker if they do not or are unable to attend
- A home visit should be considered
- A support plan should be implemented
- The carer should have a contact number for someone specialising in supporting carers
- And they should have access to the relevant information about local support groups, whether that be via leaflets, websites, etc. The best type of information source for them should be established early on.
Summary

Healthwatch Hampshire have created this report to assist directly in the commissioning decisions being made as part of the vanguard programme in relation to support services for carers in North East Hampshire and Farnham.

Over 70 carers from North East Hampshire and Farnham shared their experiences, ideas and recommendations about how support services for carers could be improved in the future. There were many recurring themes relating to the need for more respite and more financial support, as well as practical ways that health and social care professionals could help to reduce stress for carers. All of the groups also strongly emphasised the need for more emotional support but said that this emotional support could only be accessed and beneficial if the practical implications of caring are addressed too.

The support that carers need depends on the person they are caring for, the carers work, education and/or family commitments, their own health needs, their age, the amount of care that they are providing, the type of condition that they caring for and the carers emotional wellbeing. That is why it is essential that support services, where possible are tailored to meet the individuals’ needs and that carers and health and social care professionals are well-informed about the local network of support and the support that is offered is inclusive to all.
Contacts and useful links

For information about care and support available for adults in Hampshire visit:

www.hants.gov.uk/gettingstartedguide

For information about receiving support as a carer visit:

www.hants.gov.uk/carers.htm

The following charities and third sector organisations also provide further support and information:

Carers Trust - www.carers.org.uk
Carers UK - www.carersuk.org
Princess Royal Trust for Carers - www.carers.org/partner/princess-royal-trust-carers-hampshire
Age Concern - www.ageconcernhampshire.org.uk
Alzheimer’s Society - www.alzheimers.org.uk
Mind - www.mind.org.uk
Alzheimer Cafe UK - www.alzheimercafe.co.uk
Citizens Advice Hampshire - www.citahants.org

To download a copy of this report or to share feedback and experiences about health and social care services in Hampshire get in touch with us at Healthwatch Hampshire:

www.healthwatchhampshire.co.uk
01962 400262
In person at any Citizens Advice Bureau
## Appendix 1

### Engagement plan

<table>
<thead>
<tr>
<th>No</th>
<th>Group</th>
<th>Date attended</th>
<th>Brief information</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Yateley Carers Hub</td>
<td>11.04.16</td>
<td>This Hub is run by the Princess Royal Trust for Carers. Carers and cared for people can attend and speak to professionals about emergency plans, carers assessments and carer support networks. Healthwatch had an information stand and engaged carers on a one-to-one basis.</td>
</tr>
<tr>
<td>2</td>
<td>Aldershot Senior Citizens Forum</td>
<td>13.04.16</td>
<td>Healthwatch presented to over 80 senior citizens about the carers engagement work and spoke to some carers on a one-to-one basis after the event. Healthwatch was also able to promote the Carers Hubs and local groups that Healthwatch would be attending in the coming weeks, reaching out to and informing members of the community that might not have considered themselves carers previously.</td>
</tr>
<tr>
<td>3</td>
<td>Farnborough Breathe Easy Group</td>
<td>27.04.16</td>
<td>Carers and cared for people attend this group. Many that attended suffered with conditions such as COPD and chronic asthma. The majority of attendees hadn’t previously identified themselves as carers and weren’t receiving any support, so this session enabled Healthwatch to engage with unidentified carers.</td>
</tr>
<tr>
<td>4</td>
<td>Bourne Court Alzheimer’s Carers Group</td>
<td>27.04.16</td>
<td>Carers and cared for people attend this group and the focus was on engaging with relatives that care for someone living with Dementia or Alzheimer’s Disease.</td>
</tr>
<tr>
<td>5</td>
<td>Aldershot Carers Hub</td>
<td>28.04.16</td>
<td>Same as the Carers Hub above but based in Aldershot.</td>
</tr>
<tr>
<td>6</td>
<td>The Key Centre Alzheimer’s Group</td>
<td>04.05.16</td>
<td>This group was a well-established support group attended by carers and recently bereaved carers that are currently, or have cared for someone living with Dementia or Alzheimer’s Disease.</td>
</tr>
<tr>
<td>7</td>
<td>Hart and Rushmoor Young Carers Group</td>
<td>09.05.16</td>
<td>This group was attended by 12 to 16 year old young carers that care for either a parent/guardian or sibling at home.</td>
</tr>
<tr>
<td>8</td>
<td>Nepali Carers Engagement Workshop</td>
<td>25.05.16</td>
<td>This group was set up specifically for this engagement project. Both Rushmoor CAB and Rushmoor Healthy Living helped to identify and invite carers and assisted with translation.</td>
</tr>
</tbody>
</table>
Appendix 2
Promotional poster

If you are from a Forces Family and care for someone in the local community or at home, please come along and share your experiences and ideas about how to improve support for carers in the future.

Farnborough

Thursday 26th May 2016
10am - 4pm
Parsonage Farm Nursery and Infant School Community Hall, Cherry Tree Close, Cove, GU14 9TT

At the Carers Hub, you can also
- Create an emergency plan
- Access carer support and information
- Meet other carers in the local area

For more information about Healthwatch Hampshire please contact us:

www.healthwatchhampshire.co.uk
01962 440262
## Appendix 3-7

### Engagement resources

<table>
<thead>
<tr>
<th>Name (optional)</th>
<th>Age</th>
<th>Relationship to the cared for person?</th>
<th>Reason for caring?</th>
<th>How long have you been a carer?</th>
<th>Are you a...</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Retired carer</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Parent carer</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Full-time carer</td>
</tr>
</tbody>
</table>

**How do you want to find out about carer’s support services?**

Would you like Healthwatch to send you the final report about this engagement work? If so, please include your email or address.

**How could you be better supported with juggling your caring responsibilities?**

Would you like Healthwatch to send you the final report about this engagement work? If so, please include your email or address.
## Appendix 3-7

### Engagement resources

<table>
<thead>
<tr>
<th>Name (optional)</th>
<th>Age</th>
<th>Relationship to the cared for person</th>
<th>Reason for caring</th>
<th>How long have you been a carer</th>
</tr>
</thead>
</table>

Are you a...
- [ ] Retired carer
- [ ] Working carer
- [ ] Parent carer
- [ ] Full-time carer

---

**What support do you need to help you cope with the stress of caring?**

Would you like Healthwatch to send you the final report about this engagement work? If so, please include your email or address.

---

<table>
<thead>
<tr>
<th>Name (optional)</th>
<th>Age</th>
<th>Relationship to the cared for person</th>
<th>Reason for caring</th>
<th>How long have you been a carer</th>
</tr>
</thead>
</table>

Are you a...
- [ ] Retired carer
- [ ] Working carer
- [ ] Parent carer
- [ ] Full-time carer

---

**What kind of emotional support do you want most?**

Would you like Healthwatch to send you the final report about this engagement work? If so, please include your email or address.
Appendix 3-7

Engagement resources

<table>
<thead>
<tr>
<th>Name (optional)</th>
<th>Age</th>
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</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Full-time carer</td>
</tr>
</tbody>
</table>

What kind of practical support do you want most?

Would you like Healthwatch to send you the final report about this engagement work? If so, please include your email or address.
Appendix 8-11
Engagement resources (young carers)

What do you want to say to the people that fund support services for young carers in your area?

Share your ideas about how to improve services in the future!!

Have Your Say!
Thank you for getting involved!

What would the ideal support network for a young carer look like?

Add your ideas to the board, placing the most important nearest

With string, connect the services that you want to communicate with each other
Appendix 8-11
Engagement resources (young carers)

How do you want medical professionals to communicate with you and support you?

Please write your ideas all over the doctor’s white coat

Have Your Say!

What are the most important topics for you?

Take 5 post-it notes...
Choose the topics that are most important to you...
You can stick them all on one or spread them out.
Show us what matters most to you!
Appendix 12
Engagement invitation

Engaging with Young Carers and Parents
With support from Hart and Rushmoor Young Carers Group and Hart Voluntary Action

About Healthwatch...

Healthwatch England is the national consumer champion in health and care. We have significant statutory powers to ensure the voice of the consumer is strengthened and heard by those who commission, deliver and regulate health and care services.

The aim of Healthwatch Hampshire is to give citizens and communities a stronger voice to influence and challenge how health and social care services are provided within their locality. We are keen to hear about the experiences of local young carers and their families in relation to health and social care services and look at the support they receive and how it can be improved. We are currently working closely with North East Hampshire and Farnham Clinical Commissioning Group (CCG) to open up discussions with local carers about what they think is working and what could work better in the future.

About the engagement work with young carers...

At the engagement session with young carers Healthwatch Hampshire will be focussing on...

- What support services do young carers currently access?
- How could schools better support young carers?
- How could medical professionals (GP, Ambulance service etc) better support carers?
- What kind of emotional support do young carers want?
- What kind of practical support do young carers need?
- What support services would they like to see funded in the future?

Hearing the views of young carers parents too...

Healthwatch Hampshire is also very interested to hear the views of parents too. If you would like to be involved in this engagement work and have some ideas about the types of support services you would like to see developed and funded for young carers in the future please make contact with us. We are also really keen to hear about your ideas about support services for adult carers too, so please get in touch!

Please contact Laura Jones, Community Engagement Officer on 07702 3367512 or via email laura.jones@healthwatchhampshire.co.uk
We can arrange a short and informal phone call to discuss your experiences and ideas.

How will this engagement work make a difference?

An in-depth report will be written up and presented to the Clinical Commissioning Group, commissioners and stakeholders in June 2016 to influence their decisions about services for carers going forward. This report and its recommendations will also be shared with the carers, parents and professionals that have taken part in the engagement.
Healthwatch seeks the views of Young Carers

“Whether it’s improving them today or helping to shape them for tomorrow, Healthwatch is all about local voices being able to influence the delivery and design of local services.”

Healthwatch Hampshire is the independent health and social care consumer champion created to gather and represent the views of the public. This ensures changes and improvements in health services are meaningful, impactful and long-term. We are looking for Young Carers in the Farnham area to give Healthwatch Hampshire feedback on support or social care services that they may use.

Get in touch today to have your say:
01962 440 262
www.healthwatchhampshire.co.uk
enquiries@healthwatchhampshire.co.uk
Extracts from an email from Caroline Winchurch, Chief Executive, Hart Voluntary Action, in response to Healthwatch Hampshire sharing the experiences and opinions of young carers that attended the Hart Voluntary Action Young Carers Group Engagement Workshop.

...If it is possible to have this section of the report in a format that we could circulate to schools and other agencies as well that would be great.

For information, Hart and Rushmoor Young Carers as a member of the Hampshire Young Carers Alliance has recently been awarded a Big Lottery grant which will enable our project to recruit 2 new staff - one to work in schools with young carers and to raise awareness with pupils and teaching staff to help with earlier identification of young carers and one to provide direct support to families as a whole (from mid-2016 for 3 years). This may go some way to meeting some of the need identified by the young carers, but we will only be able to pay for 2 part-time staff to cover the two districts. Note that in Surrey, the County Council invests £900,000 per year in young carers' work delivered by the voluntary sector. In Hampshire it is around £160,000 so the 10 projects have to top up funding from grants.

We are also taking part in an NHS Innovations funded project to deliver WRAP sessions for young carers - the first stage is training up 2 people for Hart/Rushmoor area in using the WRAP tool and then applying this to young people/young carers' situations - this may lead to a Recovery College approach where a range of family activities to promote wellbeing are advertised/promoted. Hopefully we will be able to alleviate some of the stress side of things and embed WRAP into our ongoing work. This is piece of work will be completed by end of March 2017 and is being led by New Forest Young Carers.

There are some specific activities we could lay on such as First Aid Training aimed at young people and I hope we could ask the CCG to link up with one of their community pharmacists to ask them to come in and talk to the young carers about the medications they are having to deal with. Enabling young carers to access other after school activities would require additional resource in terms of volunteers and co-ordination time, which we don’t currently have.

It seems from the report that the young carers do have contact with their families’ GPs, but I wonder how may GPs have them registered as young carers - there is a specific NHS Read Code for this. I think I might have already mentioned that we have only had two young carers from the same family referred to us directly from a healthcare professional and that was a consultant psychologist at a London Hospital in relation to another sibling who had a wide range of medical issues which was having a mental health impact on his brothers rather than a local GP practice. Our referrals come primarily from Children’s Services, then schools and then self-referral, but never from a GP practice or hospital. Ideally young carers should be being picked up earlier as by the time it has reached Children’s Services, the family is potentially in crisis.

The other area for development, and this is something the HYC Alliance has been trying to instigate with the Princess Royal Trust for Carers is more support targeted at young adult carers, ie our young carers once they have turned 18. There is still a lot more work to be done on this to ensure that young adult carers are getting the support they are entitled to. We could do with some training for our team on carers’ rights and entitlements including their right to an independent assessment under the 2014 Care Act - Hampshire is behind on implementing this.
Healthwatch Hampshire

Appendix 15

Nepali engagement invitation

“के तपाई घरमा अथवा स्थानीय समुदायमा कसैको स्याहार/ हेर ववचार गर्दै हुनुहुन्छ?”

“के तपाई स्थानीय ठाउँमा हेर विचार गर्ने व्यक्तित्वहरूको निभ्नि आउने दिनहरूमा लागु दुने सहयोग-सुविधाको विषयमा आफ्नो धारणा व्यक्त गर्न चाहिएको अर्थमा आउनुहोस् र स्थानीय नेपाली समुदायलाई ध्यानमा राखौ नाईएको विशेष कार्यक्रम, हेल्थवच इन्ज्गेज्मेंट वर्कशेपमा सहभागी हुनुहोस्।”

बुधबार, २५ मे २०१६ (Wednesday, 25 May 2016)

दिउसोको १.३० बजे देखि ३.३०बजे सम्म (1.30pm to 3.30pm)

थप जानकारीको लागि ०१२५२ ३३३६१८ (01252 333618) मा मोनिकलाई सम्पर्क गर्नु होला

हेल्थवचको बारेमा जानकारीको लागि:

www.healthwatchhampshire.co.uk or ०१९६२ ४४०२६२

(Healthwatch engagement workshop)
Thanks

This work would not have been possible without the support of numerous people who gave up their time to talk to us about their experiences - thank you to all of the carers who contributed. We would also like to thank all of the professionals that we worked with throughout this project. Special thanks go to the staff of the Princess Royal Trust for Carers in Hampshire for their help and assistance throughout the project.

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enquiries@healthwatchhampshire.co.uk

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enquiries@healthwatchhampshire.co.uk

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