

# **Health Policy & Performance Board**

## **Scrutiny Review of Carer's Services**

**Report  
February 2017**

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## 1.0 PURPOSE OF THE REPORT

1.1 The purpose of the report is to present the findings of the scrutiny review which focused on the type and quality of Carers Services provided in Halton and the associated pathways in place to support Carers' ability to access those Services.

1.2 The full topic brief can be found at *Appendix 1*.

## 2.0 POLICY AND PERFORMANCE BOARD (PPB)

2.1 This review was commissioned by the Health PPB in March 2016. This report will be presented to Health PPB in March 2017. The report will also be presented to People Directorate Senior Management Team, Executive Board and boards or committees of stakeholders, as appropriate.

## 3.0 MEMBERSHIP OF THE TOPIC GROUP

3.1 An invitation to participate in the scrutiny group was made to all members of the Health PPB. The table below details which PPB members and officers participated in the review

3.2

Councillor Joan Lowe (Chair)	Paul McWade, Operational Director, People Directorate
Councillor Martha Lloyd-Jones	Emma Bragger Policy Officer, People Directorate
Councillor Pauline Sinnott	Mr Tom Baker ( HealthWatch)
Councillor Stan Parker	Councillor Margaret Horabin
Councillor Shaun Osborne	

3.3 **The Chair would like to extend their thanks to all of the Carers, Officers and Organisations that took time to contribute to this review.**

## 4.0 METHODOLOGY

4.1 This scrutiny review was conducted through the following means:

- Information pack provided to Topic Group Members outlining national and local picture of the impact of caring, implications of the Care Act, best practice and commissioning.
- Monthly meetings of the scrutiny review topic group;
- Presentations by various key members of staff and providers ;
- Site visits, at which there was opportunity for service-user contribution;
- Meetings with carers in their own environments;
- The final draft of this report was circulated to participating staff to check for accuracy.

4.2 The above methods enabled Members to:

- Have an understanding of the impact of a caring role on the individual, and the contribution they make to supporting the health and social care system.
- Have an understanding of the services that are available to carers to support them in

their role.

- Have an understanding of the needs of carers, what types of support are effective and where there are potential gaps in provision.
- Have an understanding of the role that all agencies, including their associated responsibilities, (both statutory and voluntary/community sector) play in the provision of Carers Services.

4.3 Members considered, in making the recommendations contained in this report.

- National best and evidence based practice, and how it can be applied in Halton.
- Ways to continue to make improvements to services for carers to ensure they continue to be effective in meeting the needs of the population of Halton.

4.4 **The Chair and members of the Topic Group would like to extend their thanks for the cooperation and contributions made by all those who have taken part in the review.**

## 5.0 BACKGROUND

5.1 A carer is anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support. Young carers are children and young people who often take on practical and/or emotional caring responsibilities that would normally be expected of an adult.

5.2 Carers are the largest providers of care and support in each area of the UK. The economic value of the contribution they make is £119bn per year.

5.3 The economic cost of carers' health, if it breaks down, could be vast since the value of the support provided by the UK's six million carers has been valued at £57 billion.<sup>i</sup> Carers' ill-health itself will place a cost on the NHS

5.4 A report<sup>ii</sup> by The Princess Royal Trust for Carers reveals that 70% of older carers suffer a devastating impact on their health due to their caring role. Based on a survey of 639 carers aged 60-94, the report found that 65% of older carers have long term health problems or a disability themselves and seven out of ten (68.8%) say that being a carer has an adverse effect on their mental health. The causes of carers' poor physical and mental ill health are due to a lack of information, lack of support – either the right kind or the right amount, worry about finances and the general stresses and strains of caring full-time with everyday life and isolation.

5.5 While caregiving can be beneficial for carers in terms of their self-esteem, it can be difficult for working-age carers to combine paid work with caring duties and carers may choose to leave paid work, or reduce their work hours. This may compromise their future employability and lead to permanent withdrawal from the labour market. The extra costs of caring and fall in income many carers face may mean they cannot afford social activities anymore, leading to a risk of social isolation.

5.6 Isolation and loneliness is something that many people face as a result of their caring responsibilities. Research reveals that 8 out of 10 carers have felt lonely or isolated as a result of caring and over a third feel uncomfortable talking to friends about being a carer.

- 5.7 The Care Act, which came into force on 1 April 2015, gives carers rights on a par with the people they care for, which includes an entitlement to an assessment of their own needs.
- 5.8 This includes taking into consideration the carer's health and wellbeing, family relationships and their need to balance their home life with their education or work. If they are found to be eligible they are entitled to support funded by the local authority. In addition, all local authorities must provide advice and information and prevent carers' needs from getting worse.
- 5.9 The Care Act 2014 places a duty on local authorities to conduct a transition assessment for young carers, when it will be of 'significant benefit' to the person to do so. Significant benefit relates to the timing when the young person is ready to have an assessment and will get the most out of the process.

## **6.0 EVIDENCE CONSIDERED BY THE SCRUTINY TOPIC GROUP VIA MEETINGS AND PRESENTATIONS**

### ***Responsibilities of the Local Authority under the Care Act - Commissioning Manager and Practice Manager Adult Social Care, Halton Borough Council***

- 6.1 The Halton Carer's Strategy was refreshed in 2016 to reflect the requirements under The Care Act and has been signed off by the council's Executive Board. The model of support for carers in Halton is based on the following principals:
- Prevention and early intervention
  - Support to care
  - Support in a crisis
  - Recognition of the caring role
- 6.2 The officers outlined that the Care Act provides a shift in legal responsibility for local authorities, with carers now being recognised in the same way as the people who they care for, and with equal rights. Statutory Carers responsibility lies with the borough where the person who is being cared for resides. Halton Borough Council has made changes to the assessment process to reflect this.
- 6.3 The assessment considers;
- The impact of caring on the carer.
  - The day-to-day life outcomes the carer wishes to achieve.
  - If the carer is able or willing to carry on caring
  - Whether they work or want to work
  - Whether they want to study or do more socially.
- 6.4 When the assessment is complete, the local authority must decide whether the carer's needs are 'eligible' for support from the local authority, depending on the carer's situation. The Care Act puts in place a national eligibility threshold, setting one national level at which needs are great enough to qualify for funded services.

- 6.5 In terms of interventions for carers, support plans look at individual needs and what would help them maintain their caring role, considering what needs can be met through existing services, first of all. The Care Act promotes personalisation, which can be achieved through the use of personal budgets/direct payments. The officers reported that Halton has one of the highest rates of Direct Payments in the country. A banding system has been introduced based on the impact of caring role on the carer, which determines the value of the direct payment, up to £300. This is in keeping with the rest of the North West. There is an 'exceptional circumstance' panel, to consider requests for creative personalised support and support which may require a direct payment in excess of £300. It was noted by the Board that the Halton approach to personal budgets is supporting a change of culture, where the level of personal budget has to be linked to level of **need**, not just a token amount regardless of need.
- 6.6 Ninety Eight percent (98%) of carers who have been assessed go on to get a personal budget paid via a direct payment in Halton. There is an audit process in place to ensure that the payments are being used to support the carer. It was reported that the Direct Payments team in Halton is well established and works well to support the implementation of personal budgets to carers. If the person requests a personal assistant they are referred to Halton Disability Partnership to broker PA support. It was reported that Halton is becoming increasingly reliant on Halton Disability Partnership and the PA brokerage service as the demand for PAs grows. The Officers noted that training for PA/carers should remain a focus to encourage more PAs to enter the market and enable Halton Disability Partnership to meet the demands.
- 6.7 For those carers who are not assessed as eligible for a personal budget, the duty of care is still met by Halton Borough Council through signposting to a range of community provision. This is followed up 4 weeks after the initial signposting to see if the carer needs any additional support.
- 6.8 In Halton there is a Carers' Joint Strategic Needs Assessment (JSNA) which provides details of the Carers profile i.e. numbers, issues and challenges for carers in Halton, which is used to underpin future commissioning decisions. This, along with the Halton Market Position Statement, helps services and commissioners shape the market of support provision for carers.

### **Conclusion**

- 6.9 The Board agreed that early intervention with carers was key to providing information and support that can help avoid carer breakdown and potential reliance on high cost services used in crisis. Linking carers' services to other prevention and early intervention work will stitch in carer support early on.
- 6.10 Responding to assessed carers needs though using social assets (ie voluntary/community sector), self-help though signposting to trusted information sources and universal and specialist services should be a priority where carers are not eligible for a personal budget. This should be balanced with the need for personalisation of support, with personalised budgets being a useful method in achieving this.

- 6.11 It should remain a priority to target groups of carers that are least engaged with support (ie male carers over 60). The need to continue efforts to engage with people currently hidden from carer services should be around an outreach approach to delivery of services in the community, rather than being building based, which may not appeal to certain cohorts of carers for a number of reasons. Working closely with colleagues and services in the Health sector (such as hospital discharge teams and primary care) will better enable carer support services to identify carers of people with health conditions at an earlier stage. Prioritising some groups of carers that find services hard to reach has been put into the Carers Centre service specification in order to address this issue.
- 6.12 Support for long term carers should be maximised through reassessment of needs at regular intervals, with potential scope for this within the follow up and review of the cared for person.

**Halton Carers' Centre Provision - *The Carers' Centre Manager, Deputy Manager and Member of the Carers' Centre Board***

- 6.13 The Board were provided with an overview of the Carers' Centre. Starting up in 2008 with a list of 500 carers, the Carers' Centre has now expanded to 5,500 carers on their caseload, 500 of which are young carers. The most recent census data indicated that 15,000 carers live in the borough, however it was noted that not all have support needs or wish to take up services.
- 6.14 The Centre is funded through a 50% match funding arrangement with Big Lottery funding, funding from Halton Borough Council, and also receives funding of £179k pa from NHS Halton CCG for staff and associated costs. Whilst there will always be a level of uncertainty associated with time limited funding streams, the Carers' Centre have responded to its own evaluation of its services, by bringing in a variety of additional funding streams, along with funds raised through events and activities.
- 6.15 A recent refurbishment of the centre in Runcorn Old Town, incorporating requirements identified through consultation with carers, now offers comfortable interview rooms, therapy rooms, IT suite and outdoor area.
- 6.16 Although the centre is in Runcorn, the centre also operates from a base in Peelhouse Family Centre on Peelhouse Lane in Widnes, which is open for carers to call into. Other satellite services are offered in Widnes, and these are promoted through partnership working and the Carers' Centre newsletter.
- 6.17 The staff team of six full-time and seven part-time staff, requires that the Centre team are extremely knowledgeable to be able to support carers of people with a number of conditions and needs. The team support people caring for people with a spectrum of needs including: learning disabilities; physical disabilities; mental health conditions and other cognitive impairments; sensory disability and substance dependency.

- 6.18 Referrals to the service come from partner organisations (ie other voluntary/community sector organisations and groups, health and social care services), outreach work at events and venues across the borough, GP practices and social media promotion. The Deputy Manager reiterated that outreach/partnership work being undertaken by the centre is fundamental and stressed that there is a need to move away from the notion of one access point, to engage different groups of carers.
- 6.19 Carers register with HCC at a rate of 80 per month and are benchmarked against a range of indicators relating to health, finance, work and social life at registration then checked again between 6-12 weeks. This initial assessment of the carer's needs is focused on a set approach, reflective of the statutory carers assessment undertaken by the local authority (ie what they are *able* to do) and what level of impact their caring role has on their day to day life. The questions asked draw out the specific needs of the carer which form the basis of a support plan used by the Carers' Centre. A six-week to twelve week review looks at their needs to see if the support put in place by the Carers' Centre is having a positive impact. It was reported that almost every carer experiences an improvement in at least one area. The Carers' Centre actively promotes statutory carer assessments from the local authority to carers, to see if they are eligible for funded care through social care.
- 6.20 The centre provides support to carers and people who are 'ex carers', through a range of interventions including: 1-2-1 assessment of the carers needs, 1-2-1 support from carers centre staff, peer support groups, day trips, activities, signposting to universal support services or specialist support organisations and delivery of holistic therapy sessions. Whilst people are supported at a distance that suits them, and the support provided changes and develops as required, all carers' needs are assessed annually in order to direct them to appropriate support as their needs change.
- 6.21 The centre strives to include carers in the development of new services and support available via the centre, and regularly undertakes feedback reviews to evaluate the services that they provide. Feedback is scrutinised to ensure that services continue to achieve the desired outcomes.
- 6.22 The Carers' Centre were able to demonstrate where they have responded to emerging needs through acting on feedback from carers. Examples include setting up a Male Carers Group, Former Carers Group (funded by a donation from HBC Community Development Fund) and Early Onset Dementia Carers Support Group. The centre has provided ADHD training, Personal Behaviour training in partnership with the Positive Behavioural Support team and a Family Dementia Carers Day.



**The difference the centre has made...**

The centre worked with The Flower and Plant Works in Church Street Runcorn to provide flower arranging courses for carers to have a break from their caring roles. One carer loved it so much that she asked for carer break funding to access a flower arranging course at Riverside College. The carer went on to open her own florist shop in Widnes.

The centre recruited and supported two volunteers who are also carers, who have since progressed to taking on paid job roles at Halton Carers Centre.

One young carer has stated that they no longer self-harm because they have now got support from Halton Carers' Centre.

The Former Carers Group has celebrated its 5 anniversary this year. They have 20 members who have restarted their lives following bereavement. This group has transformed the lives of the former carers reducing loneliness, depression and helping in the grieving process.

**Conclusion**

- 6.23 The Board were encouraged by the number of carers supported by the centre, variety of support available through the centre and the ability to respond to identified needs. The implementation of the START programme (dementia carer resilience building programme) and establishment of a younger dementia carers group were recent examples of this.
- 6.24 Access to services via the Carers' Centre should be as easy as possible, being mindful that there is a requirement to assess needs, but the centre's team have stated their willingness and flexibility to support a person through the registration process to ensure that they access everything that is appropriate.
- 6.25 The Board agreed with the Carers cCentre that there is continued need to look further at how to support those carers in transition (those 18 to 25 years old) and what needs to be done to make them aware of support available and engage them in support where required.
- 6.26 Since 2012 the Centre has been core funded through a 50% match funding arrangement with Big Lottery funding and funding from Halton Borough Council, this is to continue until 31<sup>st</sup> December 2017. It was reported by the Carers's Centre that by the end of 2017 centre will have saved HBC £649,864 in total due to successful matched funding applications to Big Lottery. The centre is currently looking to identify further funding post January 2018 for core costs, but is aware that if further external funding isn't forthcoming it may need to request financial assistance from HBC to continue providing services in Halton.

### **Role of hospital discharge teams in identifying carers of people who are leaving hospital – *Practice Manager, Halton Integrated Discharge Team***

- 6.27 The aim of the hospital discharge team is to facilitate hospital discharges in a safe and timely manner. This includes trying to reduce length of in-patient stay and to prevent re-admissions to hospital. The hospital discharge team's role is to assess adults who are being discharged from hospital, which may include people who are eligible for Intermediate Care Services (all age adults who may be eligible for support in accordance with the Care Act 2014).
- 6.28 The team also have a role in identifying carers as part of their work in establishing what the person's (who is leaving hospital) needs are upon discharge, and how they will be met by their carer and/or community services.
- 6.29 In the same way that the hospital discharge team work to support the transition from hospital back in to the community for the patient, the team look to ease the carer's experience as much as possible, however, carers' assessments are not generally done within the hospital team, the team refer onto the Initial Assessment Team and the Carers' Centre in order for these to be undertaken.
- 6.30 Whilst many of the carers the team are involved with have already had a carers assessment done previously, the Hospital Discharge Teams include carers in the patient's discharge assessment process in the hospital and they work closely with the Carers Centre and other agencies, departments and services. These include direct payments for the carer (this is a service we would commission, not a different agency), referring for a benefits check and welfare advice and respite services, with the aim of supporting carers as part of the team's involvement whilst the cared for relative/friend/family member is still in hospital, as well as after they are discharged. Community social care colleagues then follow up with the carer to ensure that they are accessing appropriate community based carer support, which is usually as part of a review process from Social Services for the Cared for, or as part of the Carers Assessment.
- 6.31 On occasion, the team are notified of discharges with little, or at short notice, however the duty worker will ensure that they action any requests for support or assessments in an urgent manner, and that the service and the carer receives the support which is required.

### **Conclusion**

- 6.32 Coordination between hospital and community remains an issue for the Board. The Practice Manager reiterated that discharge team work with health and social care in the community, district nurses and end of life district nurse liaison, to share information to enable appropriate support ie equipment, packages of care, 24hr care placement, nutrition for the patient and support for carers, once the patient has left the hospital. The Practice Manager has been involved in work led by the Social Care Institute of Excellence regarding the transition from hospital to home. Social care

staff are assigned to wards and are able to be involved in the planning of the patients hospital discharge. Currently, when someone has been discharged there is a follow up phone call 24-48 hours after, by the Hospital Discharge Team, to check that the patients' community support is in place, but it also checks support needs are being met for the carer.

- 6.33 The Board identified a potential gap that may have implications on discharge from A&E, if carer assessment/support is not considered. The Hospital Discharge Team are rarely involved in discharges from A & E as patients are not classed as being 'admitted' to hospital. The Out of Hours Emergency duty team (24/7) is in place to support out of hours discharge, urgent or crisis situations instead – they shouldn't be routinely contacted. A & E record on their system if a carer is known and will try and make contact.
- 6.34 The Hospital Discharge Team often have to work a careful balance between the patient's wants/needs and the carer's requirements ie if someone wants to come out of hospital, but the carer may feel anxious or worried about their relative/family/member returning home, they are supported by social care staff with this transition. Discharge from hospital cannot be delayed by the team where a person has capacity and is requesting to go home, but they can explore services and resources to support the patient and the carer. Strong relationships with community professionals and access to suitable carer support provision is vital to enable successful hospital discharge to happen.

#### **Health's role in supporting Carers – *Chair of NHS Halton Clinical Commissioning Group (CCG)***

- 6.35 The Chair of the CCG informed the Board there is a specific person at the Carers' Centre who is a liaison worker who works with all the GP practices in Halton, to foster the connection with GPs, raising awareness of carer services and encouraging referrals to the Carers Centre.
- 6.36 GP practices had a system for sharing carer information with the Carers Centre, with the carer's permission. There were about 2000 people identified as carers in 2010, as the current GP practice system of working with GPs started there was a regular influx of carer details from the GP practices into the Carers Centre, raising the number of known carers to over 5,500 over 2/3 years.
- 6.37 The number of known carers to the carers centre, as a proportion of the projected number of carers in Halton, is actually considered quite high. They currently have an active case load of in the region of 5,500, 495 of the carers are under 18. In 2015/16 the GP scheme identified 142 people who were not previously registered. An additional 98 were also referred, but were already registered, but the re-referral enabled a review of the support. Since April 2016, the average number of carers referred each month from GP practices is 19.
- 6.38 A gap had been identified around hospitals and identifying carers. The Carers' Centre has 5 areas with specific staff: Mental Health, Dementia, Primary Care, Hospital Liaison and Young Carers. The staff regularly attends clinical groups and patient groups so that they can build relationships to encourage more referrals from both

primary care and the hospitals. However, in the CCG's Chair's view the hospitals need more work to make referrals; referrals primarily come from the Carers' Centre worker being in situ or from carers info/posters in the hospitals, rather than hospital staff.

- 6.39 GP practices have Multi-Disciplinary Team (MDT) meetings where the Primary Care Carers' Centre staff member attends at 10 of the meetings across Halton. Within the MDT discussions they will identify new carers, or changes in the status of the carer. MDT meetings try to head off crisis, identify early interventions etc. There are 6 practices that currently do not have this Carers' Centre coverage in MDTs. The Carers' Centre Primary Care worker spends time in practice waiting rooms, especially when there are clinics on such as the flu jab clinic, to try and engage with carers. Carers are also notified of things like the flu jab through the carers newsletter – two way communication.
- 6.40 A weekly email is sent to practice managers, district nurses etc to remind them of the Carers' Centre support or relevant carers information, to build relationships.
- 6.41 The CCG Chair's view is that Halton is working hard to make connections between the Carers' Centre and the GP practices to increase referrals for carers support. The CCG are in regular contact with the Carers' Centre to see how improvements can be made. The CCG Chair is confident that Halton, in comparison to other areas, has got quite well established relationships and processes to support carers.
- 6.42 To put the contribution of unpaid carers to the health and social care economy into context, the CCG Chair quoted some research figures in relation to the cost to the nation. In some research, the value of unpaid care has been costed at £63bn, nationally. It was highlighted that many carers do not identify themselves as carers, particularly parent carers, and this can impact on the carers accessing support.
- 6.43 The Wellbeing Practice Model (Wellbeing Enterprises) is wrapped around each practice, and the feedback is positive and wellbeing scores are being increased through various initiatives. Within the first 18 months of the wellbeing enterprises offer, 75% of people accessing support were carers.
- 6.44 The Board referenced the importance of supporting ex carers ie help into employment, health and wellbeing support, as well as bereavement support. There is a risk of social isolation as a carer when their loved one has died. The Men's Shed was cited as a good example supporting male carers and ex carers.
- 6.45 The CCH Chair reported that GP practices do signpost carers to counselling and bereavement services, wellbeing enterprises etc for carers who re expressing concern about social isolation and bereavement. GPs are aware of mental health problem risks with carers, ie a higher chance of being depressed.
- 6.46 The Board asked the CCH Chair about what is happening with links with schools for younger carers. The CCG Chair confirmed that the CCG do not have any formal connections with schools, but school nurses and school pastoral care systems do identify young carers, which will link young carers into services.

- 6.47 In relation to data protection issues between the carer, cared for person, and GP, the GP should understand the relationship between the patient and carer, and get informed consent from the person for the carer to take part in the discussions. Mental Capacity issues need to be clarified. If the cared-for person has not got mental capacity the GP needs to understand who is acting on their behalf, legally and log it in the patient notes.

### **Conclusion**

- 6.48 The Board commented on the considerable saving to the health and social care services by family members picking up caring roles. The gap between hospital and community can be difficult for carers to negotiate. The Board agreed that it is important that work is done with the Hospitals to work on that.
- 6.49 The Board accept that the Carers' Centre do not, and cannot, see every carer, the Wellbeing Enterprises within GP surgeries should continue to supplement the support that the Carers' Centre can offer. The Board agreed that the Health of the carer is important and should be recognised as such
- 6.50 The Board discussed that Members are well placed to support links with schools as many of them are Governors. The board did give examples of local Academies that did refer into carers services. The Board recognised that support for young carers is important to maintain their own mental health. The CCG give out Wellbeing Awards and The Health School got an award last year for what they do to care for the staff and children.
- 6.51 Whilst it is recognised that the Carers' Centre is very proactive, particularly with the GP practices, both the CCG Chair and the Board recognise that more energy at the hospital level would be beneficial. There is a need to raise the level of accountability for hospitals in identifying carers, and understanding what the hospital's offer to carers is, when they are in the hospital. There remain questions about what happens with carers, proactively, whilst someone is in hospital? Hospital discharge teams are only one part of the support.
- 6.52 Carers recognising themselves as carers is an issue, especially with younger carers. An engagement campaign may go some way to overcome this. The Board acknowledged that it is not possible to engage with all carers as there will always be a cohort who will not recognise themselves as carers, a cohort that doesn't want/need support etc.

## **7.0 EVIDENCE CONSIDERED BY THE SCRUTINY TOPIC GROUP PROVIDED BY CARERS**

- 7.1 During July/August 2016 members of the Board met with two individual carers to gain an insight into the impact of a caring role on the carers' life and own health and wellbeing. The meetings were held at times and locations determined by the carer, within the community. The meetings were kept informal so the comfortable approach was able to get the most out of the opportunity to talk to people who had taken time out of their caring role, and were attended by a scrutiny group member and Policy Officer (note taker). There were no set questions, meetings took a conversational approach and were led by the experiences of the carer.

7.2 A summary of the meetings with carers can be found in *appendix 2*.

7.3 A number of common themes came out through conversation, including:

- Carers' grants, breaks and respite are a valuable support, providing a much needed break from routine.
- Use of carers grant/break funding is really useful to achieve personalised outcomes that can't be met through existing provision.
- Quality / availability of support for the cared for person is critical to the health and wellbeing of the carer. Where there are gaps in services or quality carers reported that this had a direct impact on their health and wellbeing in relation to stress and demands on their abilities as a carer.
- Whilst one person may have a more clearly defined caring role for the other, carers and the cared for person are often interdependent on each other. When carers themselves have health and wellbeing needs, this can impact on their ability to care for the other person, which may result in the cared for person caring for the carer to some extent.
- Agencies that support carers which have a sound understanding of the individual carers/cared for care arrangements, and how they work, are best placed to support carers when things change. Agencies that understand the individual carers specific role in supporting the cared for person are best placed to identify in a timely manner when things are going wrong, or changing, so to support the carer to make changes or get additional information, support etc.
- Being a carer for a family member is seen as a 'duty' by some, which can bring with it added pressures. One carer referred to their caring role for a family member as being "a thankless task". Carers of family members are working on 'motherly duty', or similar, and without guidance or support.
- Friendships and peer support are valuable for the carer, to share experiences and support each other, but outside of the care environment.
- It can be difficult for carers to sustain employment alongside their caring role.
- Carers gain strength, and feel supported, when they feel that their loved one's needs are being appropriately met.
- Courses and sources of information about conditions are useful for carers, helping them understand and equip themselves to support their loved one.
- Health and social care services need to be joined up so that carers do not slip through the net
- Easy access to carers' services is essential, without the need to repeat the carers/cared for history.

## **8.0 EVIDENCE CONSIDERED BY THE SCRUTINY TOPIC GROUP VIA SITE VISITS**

8.1 In July 2016 members of the Board visited Halton Carers' Centre and met with staff and carers to gain an understanding of the range of provision provided by the centre, and the impact of taking on a caring role.

8.2 Below are some comments and themes that were picked up from the visit:

- Those who had been assessed reported that it was an effective process that led to them feeling supported.

- Carers should be made aware that they are eligible for a statutory carers assessment from the local authority, which is different from registering with the Carers' Centre.
- The Carers' Centre staff were praised for their knowledge and responsiveness by the carers who were spoken to on the visit.
- The needs of young carers and carers in transition from children and young people's services, to adult services, need to be considered further, with a younger carer reporting that she often has to "fit in" with support and services geared towards older carers.
- The carers reiterated the need for the Carers' Centre and the benefits that the services bring to carers.
- Finding carers who are 'hidden' is important so that they know what support is available, if they want it.

## 9.0 RECOMMENDATIONS TO HEALTH PPB

1	<p><b>There should be a continued focus on provision of information and support at the right time for the carer, to avoid carer breakdown and use of high cost services.</b></p> <p>Prevention and early intervention services and organisations across health and social care should consider how they can proactively identify and engage with carers to be able to sign post them to/provide information that can support their caring role. Services should be able to demonstrate how they do this.</p> <p>Prevention and early intervention services are well placed to enable carers to have access to information and support at an early stage, which may help to mitigate progression of a crisis situation for the carer.</p>
2	<p><b>Continued efforts to engage with people currently hidden from carer services.</b></p> <p>Key stakeholders, including Social Care, NHS Halton CCG, GP practices, local acute trusts, Halton Public Health, the Halton Integrated Wellbeing Team and providers such as Wellbeing Enterprises should work collaboratively to:</p> <ul style="list-style-type: none"> <li>• Identify carers and promote available support to all parts of the community.</li> <li>• Develop innovative approaches to delivery of services in the community, in order to appeal to the diverse needs of carers in Halton.</li> <li>• Raise awareness, not only of information and service provision to support carers and professionals, but also <i>of what constitutes a carer</i>.</li> <li>• Work with partners in Children's and Adult's Services to embed the newly developed 'transition protocol', engaging with children at an earlier stage to plan for their transition into adult services, including carers support services where they are identified as being a 'young carer'.</li> </ul>
3	<p><b>A renewed focus on relationships with health, in particular the Hospitals, to encourage identification and support of carers.</b></p> <p>Whilst acknowledging that the Carers' Centre and GP Practices have well established and successful relationships in identifying and supporting carers, efforts need to be focused towards working with the local acute trusts.</p>

	<p>Carers are frequently identified through social care assessments, but less so for carers of people with health conditions.</p> <p>Health and Social Care Senior Management should consider carers, as a standing agenda item at existing meetings. This may include how to work with partners, including the acute trusts, to build awareness of the role of, impact on and needs of carers, promote what support is available locally and strengthen relationships between the hospitals and carer support services.</p> <p>Services and agencies that support carers should work with acute trusts to help them better understand how hospitals can identify and support carers whilst their loved one is in hospital, and throughout the discharge process.</p>
4	<p><b>Assessment of long term carers needs at regular intervals.</b></p> <p>Consider the scope within the annual review of cared for people to systematically offer an assessment to their carer, where previously it had been declined by the carer or they were previously not eligible.</p>
5	<p><b>Involving carers in coproduced service development.</b></p> <p>Examining and adopting different ways of engaging with carers in consultation and co-production of service developments. This may involve training and support for carers to take part in consultation and coproduction exercises.</p>
6	<p><b>Ensure that within carer provision there are a range of different interventions to meet diverse and changing needs of carers.</b></p> <p>Whilst there are no immediate plans to reduce the level of investment in carer services, Commissioners of carer support services and carer support organisations should consider how available resources are invested to be able to continue to deliver <i>different types of support</i> (ie 1:1, personal budget, carers breaks, peer support social groups). Services should also consider post caring support needs of carers ie after a bereavement.</p> <p>The variety of support not only needs to provide information and practical help for carers in their caring role, but should also consider wider factors including the mental health, social inclusion and employment potential (where appropriate) of carers.</p>
7	<p><b>Consider how access to carers services can be improved.</b></p> <p>Carers reported that the lack of a single point of access, or named care coordinator for carers is a cause of frustration to some. Further work should be undertaken with agencies that support carers to consider how they can work together to ‘mesh’ services so it doesn’t matter where people enter, they will get consistent and appropriate support.</p>



## Appendix 1 Scrutiny Topic Brief

<b>Topic Title:</b>	Carer Services
<b>Officer Lead:</b>	Paul McWade – Operational Director, Commissioning & Complex Care: People & Economy Directorate
<b>Planned Start Date:</b>	April 2016
<b>Target PPB Meeting:</b>	March 2017

### Topic Description and Scope:

This topic will focus on the type and quality of Carers Services provided in Halton and the associated pathways in place to support Carers' ability to access those Services. It will examine these services and associated pathways, with a view to evaluating their effectiveness in meeting the needs of the local population.

### Why this topic was chosen:

The Health Policy and Performance Board recognise and value the essential role that carers play in supporting some of the most vulnerable people in our community.

The 2011 census found that there were over 15,000 carers in the Borough who were providing unpaid help and support to their partners and relatives etc.

- Approximately 8,000 individuals provided unpaid care for 1 – 19 hours per week;
- Nearly 2,500 individuals in Halton provided unpaid care from 20 – 49 hours per week; and
- Over 4,500 individuals provided unpaid care for 50 or more hours per week

It should be noted that approximately 3,000 carers were aged 65 and over.

With the introduction of the Care Act 2014, Carers are now recognised in law in the same way as those they care for; this means they have the right to an assessment of their needs. As a consequence, the Act has resulted in an unprecedented focus on Carers and their own health and for the first time sets out a set of national criteria to establish whether the Carer is eligible for support. If this is the case they are entitled to a Carer Support Plan and a further review of their status after 6 to 9 weeks. The purpose of this review is to see whether the impact of their caring role is still significant.

It is felt that this Scrutiny topic will provide the Board with the opportunity to actively contribute to the review and development of a new service specification for the Halton Carers Centre and development of a Carer's Strategy, which have been identified as key developments in respect of Adult Social Care during 2016/17, as part of the Business Planning process, in addition to ensuring that the Local Authority is discharging its duty in respect of Carers as outlined in the Care Act 2014.

**Key outputs and outcomes sought:**

- An understanding of existing Carers Services available in Halton and associated pathways for Carers to be able to access them.
- An understanding of the role that all agencies, including their associated responsibilities, (both statutory and voluntary/community sector) play in the provision of Carers Services.
- Ensure services provided take into consideration national best and evidence based practice.
- Consider ways to continue to make improvements to Carers Services in Halton to ensure they continue to be effective in meeting the needs of the population of Halton.
- An understanding of the different elements of service monitoring that take place in respect of this area of provision.
- Identification of the best methods for measuring the outcomes for Carers.
- Outcome of Scrutiny review to contribute to the development of the new service specification for Halton Carers Centre and the development of Halton's Carers Strategy.

**Which of Halton's 5 strategic priorities this topic addresses and the key objectives and improvement targets it will be help to achieve:**

**A Healthy Halton – To improve the health and wellbeing of Halton people so they live longer, healthier and happier lives**

- To understand fully the causes of ill health in Halton and act together to improve the overall health and well-being of local people.
- To respond to the needs of an ageing population improving their quality of life and thus enabling them to lead longer, active and more fulfilled lives.
- To remove barriers that disabled people face and contribute to poor health by working across partnerships to address the wider determinants of health such as unemployment, education and skills, housing, crime and environment.
- To improve access to health services, including primary care.

**Nature of expected/ desired PPB input:**

Member led scrutiny review of Carer Services and how these Services can be accessed.

**Preferred mode of operation:**

- Meetings with/presentations from relevant officers from within the Council and partner agencies to examine current services.

- Visit to Halton Carers Centre/Other Carers Centre.
- Carer Interviews.
- Desk top research in relation to national best and evidence based practice.

## **Appendix 2 Notes from meeting with Carers**

### **Notes of the meeting with Carer C.**

**Tuesday 19<sup>th</sup> July at 11 am**

Those present: Carer C, Councillor Joan Lowe (JL), Councillor Shaun Osborne (SO), Emma Sutton-Thompson

Councillor Lowe began with introductions and an explanation about the Carers Scrutiny Review that is being undertaken by members of the Health Policy and Performance Board. Any recommendations regarding improvements for carers in Halton will be included within the final report and presented to the Health Policy and Performance Board and the Executive Committee for their approval.

At the beginning of the meeting, Carer C gave permission for information she provided to be included in the scrutiny report.

Carer C began by giving some background to her situation – “my son was 14 when he first became ill and wasn’t able to finish school. He’s 31 now. At that time, I didn’t know where to go for help. The school suggested we contact the GP and he signposted us to Thorn Road Clinic which really helped him to understand things. He then went to the YPC in Chester for diagnosis and assessment and was assessed with schizophrenia which we were not expecting at all. My son has been so much better since he’s been living in the community, he’s been out of hospital now for 15 years, apart from a brief spell when his medication wasn’t working so was changed. Now it is so much better and easier for me too. It used to be a 24 hour job for me. When my son was 18 they got him a flat, but he still needed lots of help, things like washing, shopping and cleaning. He was living on his own, with Outreach help. I was there a lot. My son couldn’t focus on what he needed to do or the order in which to do them. I felt I had to teach him how to be independent. Over a long period of time, he made improvements with some set-backs. PSS helped with him getting a bus from his flat to my house, and they helped him in the flat. It took 12 years before he was able to do a shopping list himself and go shopping. I had no support as a carer.”

**JL** – Asked how this could have been improved for Carer C. “Someone to go in 2 - 3 times per week would have given me a break, but I couldn’t see how the staff would have the time. Now I don’t have to do as much as I did. I only see him at weekends. He has a befriender in the week from MIND – they go out to play pool or to have a meal.”

**JL** – Do you have any contact with the Carers Centre? – “Years ago I had contact with the Carers Centre, I was on the Carers Strategy Group and forums. I also had an illness myself

which took over for 5 years, but now I am on the right medication. If you look after someone on your own with a severe mental illness you'll end up with a mental illness yourself. Once my son phoned the crisis team and they told him to phone me! He acts upon the thoughts he gets (not voices). One day at his flat he was calling out loudly – I rang the outreach team as I knew he was very vulnerable, I was told it was not a 24 hour service. He wanted company, so I stayed within him on my own until he was ok. That was 6/7 years ago. One positive – I called the crisis team, two people came out and asked what help was needed. That was exactly what we needed to hear. My son has recently changed his drug and now doesn't have the thoughts, but he has put on six stone in weight. He's now on the Fresh Start programme which is run by the Council and he's lost 6 pounds. Now I only visit at the weekend, there's only the two of us in the family locally. Once a day we (my son and I) phone each other to check each other is ok. If there was a crisis now I would look for help. Earlier this year I had a crisis with myself, I have bi-polar disorder. My son looked after me, but one day he didn't feed me. He knew something wasn't right so he phoned the CPNs, our keyworkers and told them I was really poorly. . The keyworkers have the knowledge of how my son and I work together to look after each other.

**JL** – That's lovely that you support each other. You should be proud of the achievement you've both done.

**SO** – People don't realise the hard work it takes, you are a family member and a carer and it takes it toll.

“My son has made marvellous improvements and now he can help me. The best thing was a social worker years ago who sorted out his flat. He had to learn about remembering to take his keys and locking doors, etc. He now has appointees to sort out his finances, though advocates. He knows all about scams and how to deal with them. He says let the phone ring and it will stop. After my son was in the YPC in Chester, he then went to the Brooker Centre, after a year a nurse wanted to put him in an institution, but I said no. I wanted him to have care in the community. Sometimes it felt like a thankless task, although he is better than he was he is still very dependent on me. I help him with his mail and sorting through letters, but he's about 80% self-sufficient now.

**SO** – As a carer is there anything that would help you now? - Yes, having a break so that I can then help again. Sometimes I had no sleep as I was dealing with my son through the night, or worrying about him. Just having a rest, even an afternoon would have helped.

**JL** – in the position that you are in now, what do you think would help? – Having the befriender, the outreach worker and me helping. I just check he's ok and make sure he is on track.

**JL** – do you go out much yourself? – I have 3 friends who understand my situation and we go out shopping or for a meal to support each other. We are all single ladies. As carers we have received a grant, we went to London for 3 days and it was a lovely break. Some people say how could it be a break when you're with the person you're caring for, but I didn't have to do the washing up or shopping, so it was a lovely break. A very positive experience.

**JL** – do you have community groups that you can access? – I want to write a book, I did attend a writing group, but they weren't serious at writing, so I'm trying to do it freelance now. I like to read as well. I went to University in 2010 and did a course in leadership in Mental Health. Half-way through I had bi-polar for 2 weeks, but managed to get myself back

on track. When I was caring I was just using motherly instincts – I had no help or guidance on what I should be doing. I had to take calculated risks myself, for example, with my son crossing the road or making a cup of tea. I used to repeat things over and over again.

JL thanked Carer C for her time today and the valuable contribution that this will bring to the carers scrutiny review.

### **Notes from meeting Carer S**

Present:

- Carer
- Service-user
- Cllr Margaret Horabin
- Cllr Joan Lowe
- Nicola Hallmark – Principal Policy Officer (minute-taking)

Date: Wednesday 20<sup>th</sup> July 2016 – 1pm to 2pm

Venue: Coffee shop in Widnes. The carer and service-user are co-habiting partners living in Widnes. They met almost 17 years ago and at the time the carer said she had very little understanding of her partner's condition. The service user has schizophrenia and is currently stable on fortnightly injections.

The carer spoke freely and openly of her journey and experience of caring with some further prompt from Cllr's Lowe and Horabin.

She began to unfold her story in relation to her current business interest. She said that this has given both her and her partner a focus. The carer expressed that her business had run for nearly 10 years and followed an assessment for carer's funding where the assessor had asked her what she'd like to do. Over a period of two years the carer used her carer's fund allocation to undertake two courses then was able to set up her business. Her partner helps out with the business and she said that this is great therapy for him. The carer said that the way they had used the fund to achieve this goal was, "absolutely fantastic, the best thing that had happened in a long time."

The carer and her partner have two dogs and she uses their needs to motivate her partner's. "He has to get up and do walks in a morning." She stated that the business provides additional structure for him. They have some regular clients but it can also be patchy dependant on the time of year.

In addition to the business the carer currently works one day a week (24 hours shift) for a care agency. She used to do two but was unable to sustain this because of her caring responsibilities.

Services have diminished over a period and while the service user had provision of care during the carer's paid working day this is now ended. The carer told us that he had had a Support Worker for a time. This was for around 1 to 2 hours when she was at work on the Monday. They would go for a coffee and a chat and it was a good outlet for him and she knew he was safe during this time. The Support Worker was then pulled and he was changed over to a Mental Health Social Worker. There was no change for her at that time as she was

secure in the knowledge he was still supported. After a time however this was pulled and her understanding was that this service is only open to in-patients for a period following discharge. The carer is left concerned that there is no cover for her partner during her working hours. The carer suggested that this provision was vital and gave her partner a chance to off-load from a different perspective.

The carer and her partner have friends whom they can both chat to but don't feel this is the best channel for unburdening in relation to issues encountered as a result of the condition being managed. Removal of provision has taken away a single point of contact for them both in respect of contact with services. The carer expressed that her only source now is the Crisis Team – and this inevitably is when they've reached crisis.

The carer said that in the past year a new post has been put in place which helps (Carer's Development Worker) with carer needs but for herself it's more about managing her partner's needs. She said that she doesn't need to off-load herself so doesn't tend to access services herself.

At the start of her caring journey the carer engaged successfully with the Carer's Centre and was signposted to a course. This offered her insight into schizophrenia and the pathways for getting help. The carer admits knowing very little at the time and as a result of attending the course was better equipped to support her partner. During one of his hospitalisations she was able to access advocacy services and said she wouldn't have known about this were it not for the course. She has not taken up any of the complimentary therapies for carers as feels she's not got time because of her caring responsibilities. More recently she hasn't seen any other training that she feels would be useful.

The carer stated that she had reached a bit of a crisis point herself and visited her GP. She is now on anti-depressants to "help deal with the stress of the situation." She described that she had become unable to sleep at night and got anxious and in a rage. She said that she doesn't feel like that now but "doesn't want to take the chance of coming off" her medication for fear that she will return to this state.

Some discussion took place over whether the Carer's Centre was now closed. Confirmation was given that the Carer's Centre in Runcorn was now fully open after refurbishment. The carer was urged to re-engage with the service. She said that she thought it was fantastic for new carers but "not much use" for established carers.

The carer spoke of an issue in work, prior to her anti-depressant medication, where she'd got angry. She did contact the Carer's Centre on that occasion and they supported her by helping with a response letter. She said she "felt relieved there was something there when needed." The carer reiterated her concern that there's a lack of support for her and her partner prior to reaching crisis point. She feels that the health service and social care provision are not fully tied together and this leave them wanting for a point of contact. At times the carer has been in touch with services and asked for previously known workers. That way she knew they had knowledge of her partner's case.

She said that the idea of services previously (Support Work/SW) was to support her partner to support himself. She's acutely aware however that he's "never going to be able to function properly," and in that way there needs to be more support for ongoing need rather than rehabilitation. He is under psychiatric services for his medication but has received no social care support for the past 5-6 months. This has not made much difference to her at present,

as he is stable on current meds, but she said that “it feels wrong that there’s no support.” It does add pressure to some extent however and the carer said that when she’s not spoken to him all day she has to make contact to check on him. She tries her best to track his “frame of mind” in order to monitor change. She feels that she has to “go to work in the morning and just hope everything is alright.” She will make suggestions as to activity during her working day but she’s not aware of whether he takes them up. She manages the rest of his week more closely to “keep him moving and motivated.”

The carer spoke of the strain of caring responsibilities on their relationship. She expressed difficulty with aspects of his behaviour resulting from his condition. She said that she’s “not just a carer but part of a couple and this is a lot to get your head around as I need to emotionally cut-off. When nasty things come out you have to think ‘it’s not meant for me’. I have to box it off. When you’re with your partner they’re everything to you. We do get on well and I’m with him 24/7 until Monday when I go to work.”

When asked about how she winds down she said she has a drink on a Tues and a Fri – as she doesn’t drink before work. She has a garage which is her ‘chill out space’ where she sits with friends. She also likes to watch horror movies and her partner tends to go to bed and leave her to it.

She was asked what support she would like and she said that a single point of contact is vital so they don’t have to go through his history all over again.

The carer feels she is strong and would ask for help if needed but doesn’t tend to bother with smaller groups or networks as neither has the time or sees the benefit. The couple were going to join the gym but never got round to it. They are aware that there are some services that they could but don’t access.

A carer’s assessment has been undertaken and the carer continues to take up the carer’s break money. This is invaluable to the couple who take two breaks a year in a log cabin in the Lakes with their two dogs. She did say that the amount has reduced and this adds pressure as it used to pay for the petrol also or a meal but now they have to save.

The couple receive working tax credits because of the carer’s low income. The service user also receives Disability Living Allowance. The carer owns her own house and expressed that she feels ‘lucky’ to be in this position.

The carer said that she has considered supporting others she knows but then has to draw herself back as knows “it’s too much” to take on.

The Councillors agreed they had the information they needed for the scrutiny review and that the carer’s comments would feed-in to their overall recommendations.

CLlr Lowe explained the scrutiny process to the carer along with the reason why this topic has been chosen for review. She explained that the review will be a public document and asked the carer whether she wanted to be named. She expressed that she would prefer to remain anonymous.

The carer and the service user were thanked for their contribution.

**Notes from visit to the Carers’ Centre**

## Health PPB: Carers Scrutiny Review Carers Centre Visit (Runcorn) 26<sup>th</sup> July 2016

Present:

Cllr. Pauline Sinnott

Tom Baker (Healthwatch representative)

Natalie Johnson, HBC Policy Officer (notes)

Cllr. Sinnott and Natalie were welcomed to the centre by Carl Harris (Manager) who confirmed that he and his colleague would be attending a future meeting of the topic group and would be able to share the results of a recent survey with carers. Today, he had arranged for a group of carers/cared for people to be available for a general discussion.

The meeting began at 1:00pm with Cllr. Sinnott introducing herself to the group of carers/cared for people and thanking them for attending the meeting. She explained that the role of the Health PPB is to scrutinise local services. Cllr. Sinnott has a particular interest in the centre being one of the ward councillors for the area and also because she was a carer herself until recently. It was clarified that the purpose of today was not to scrutinise those attending the meeting but to find out about their experiences, views etc.

Cllr. Sinnott explained the aims of the scrutiny topic and the subject areas to be considered as outlined in the information pack for councillors.

There were introductions around the room:

L and his son (carers), L's wife is on the 'Forget me not' ward, "Lucia from the centre is doing a brilliant job supporting the family"

P (cared for) and his daughter S (young adult carer)

M (cares for his wife) and his daughter B (young carer)

J (carer) and his wife (cared for)

B who cares for her husband who has Alzheimer's

P who cares for her mum and brother and also runs a support group and works at the centre as well

S who cares for her husband who has dementia

Cllr. Sinnott suggested the group discuss the recent change in the law brought about by the Care Act in terms of **carer's assessments** – has everyone had a statutory assessment from the Council (it was clarified that this is different to registering with the centre)?

- S and B said they had not had one;
- P explained that you have to request one, they're not automatic like they used to be;
- Other members of the group reported that they had been assessed, usually through the cared for person's Social Worker;
- Those who had been assessed reported that it was an effective process that led to them feeling supported;
- Cllr. Sinnott suggested that this is an issue that could be raised with staff at the centre and they will be able to advise how to go about getting an assessment. These assessments are important as they recognise the rights and needs of the carer as well as the person they care for.



- All carers upon registration with the centre and during review are asked if they want to be referred to HBC for a carer's assessment. It is also included as an article in the carers centre newsletter from time to time informing carers of their right to an assessment as well as in our information pack that all carers receive upon registration.

Cllr. Sinnott asked the group for feedback on **sources of information** and **how easy people found it to access the centre**:

- People reported that without Lucia they wouldn't know about anything (support etc.)
- Everyone feels listened to at the centre, staff will help in any way they can, nothing is ever a problem, you don't get 'fobbed off', it doesn't matter how minor or major your issue is staff will always put the effort in to help you and they help with any issues and they are quick in the help and support they provide;
- It was reported that schools refer young carers to the centre and there are posters in GP surgeries etc. and often when Social Services visit the cared for person, they refer the carer to the centre;
- Carers think it is their 'job' to care (i.e. they don't recognise that they are a 'carer') so don't realise that help and support is available;
- Social Workers and GPs are better at referring to the centre but there isn't consistency in the information available;
- J and his wife reported a poor experience on her discharge from hospital (no support, GP unhelpful);
- Mixed experiences from different GP practices – a GP at New Town, Widnes is very supportive of the carer role and ensures support is being accessed, at Beechwood (Widnes) there are messages flashing up about the centre, however, at Hallwood (Runcorn) GPs don't refer to the centre although leaflets were available;
- It should be fed back to the CCG that some practices are not promoting carer's services/support (individual experience can depend on the interest/expertise of the particular GP).

Tom Baker arrived 1:25pm, Cllr. Sinnott introduced Tom to the group and re-capped on discussions that had already taken place.

There was some discussion around **eligibility for accessing funded services through HBC**:

- Three categories – not sure if categorising is appropriate;
- Cllr. Sinnott read the information on eligibility within the topic group information pack – someone is likely to meet the criteria if there is a significant impact on their wellbeing as a result of their caring role.

Cllr. Sinnott asked the groups where the **gaps** are in terms of services/support for carers:

- S felt that there is nothing for young adult carers (i.e. aged 18-25) and she has to fit in with groups aimed at young people (teenage carers) or older people, which doesn't fit with her own needs/interests. It has been suggested that S set something up but she feels that she needs the support and therefore not able to provide the support to others. S sees things taking place in other areas;
- It was agreed that in some cases there isn't the right kind of specific support and if you haven't got the resources etc. to set something up then you are not supported but services should fit with you not the other way round;

- There was some discussion around the stigma that is attached to being a young carer – B and S are involved in work making use of the Internet to try and tackle this issue and make support for young carers more appealing (there was a suggestion around young carers linking in with older age groups to support with technology);
- There was a general feeling in the group that it should be a national commitment that young people shouldn't have to take on an unpaid caring role although the group applauded S and B for what they do, which they feel is 'normal' / 'natural'. It was noted that some young people can cope but others might not be able to and there should be support out there for them and the Government should not put that responsibility on young people. It was noted that these are important issues but we can only make things better at a local level.

Cllr. Sinnott asked the group about their experience of **respite** (e.g. carer's breaks):

- Sometimes other family members have to step in to provide care (e.g. 'my mum won't have anyone else coming in'), which presents a barrier for the carer;
- S reported that her husband doesn't recognise his own illness so he won't go into respite, he thinks he can manage and if it's suggested that S needs a break he says 'we will go then', the only respite S has is a coffee morning or a meeting like today but she can't leave her husband for an entire day;
- There is a sense of responsibility – 'my mum brought me up so now I'll be there for her' – but it does take its toll and you need a break to 're-charge' and enable you to continue caring;
- One person mentioned day centres that used to pick people up but they are now closed;
- J reported feeling like he had to be strong for his wife and he was bottling things up but one day he asked to leave the house for a while and he just screamed to let everything out, he needed that 'release';
- It was felt that sufficient funding should be there. L's wanted to mention the 'Disabled People Against Cuts' (DPAC) group – they have a website and Facebook page, they lobby Government.

Cllr. Sinnott asked the group if there was **anything else** they wanted to mention:

- 'Don't let this place (the centre) go!'
- Need to find the 'hidden' carers who aren't receiving support;
- 'How will we know the outcome of this?' Cllr. Sinnott assured the group that the centre would be sent a copy of the final topic group report (overall it is looking at wider remit, not just the centre), although it is a public document as well;
- P mentioned that she is attending the Carers Strategy Group (led by Paul McWade) and they are looking for a wider group to get involved (currently just mental health and learning disability carers). It was noted that the group should perhaps come to the centre like today's meeting as it can be daunting for carers to attend council meetings.

Cllr. Sinnott thanked the group for their attendance today and confirmed that the findings from today's discussions and the other elements of the topic group would be fed back to the Health PPB in the final report in order for them to decide what actions take place – thank you for having your voice heard and feeding back your views!

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<sup>i</sup> Carers UK (2002) Without us...? Calculating the value of carers' support, Carers UK

<sup>ii</sup> "Always on Call, Always Concerned"