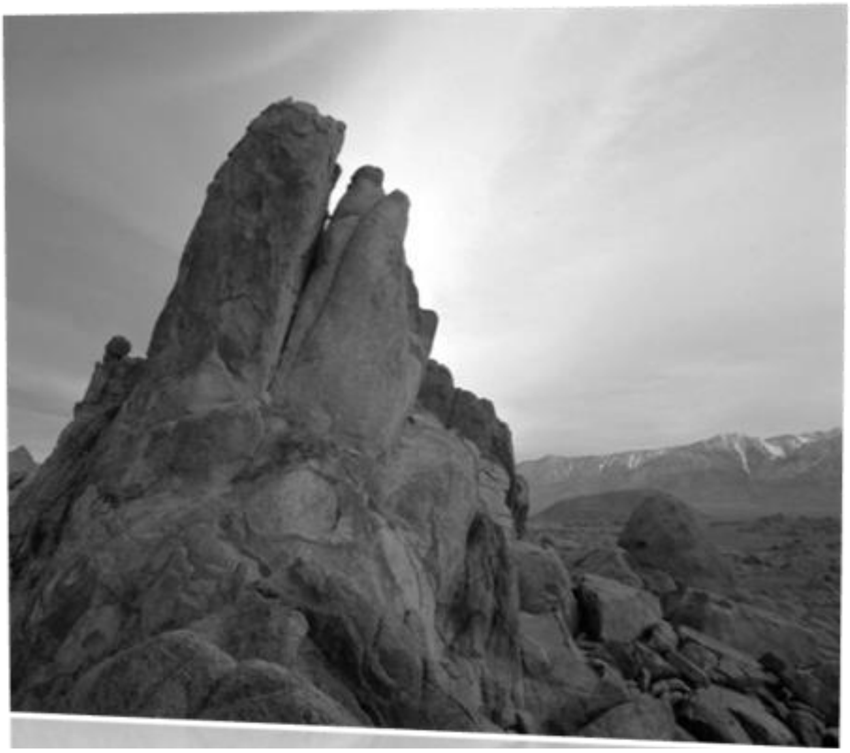

An Evaluation of Mental Health Carers' Assessments and the Triangle of Care in Shropshire

An Evaluation of Mental Health Carers' Assessments and the Triangle of Care in Shropshire

A 2-part investigation looking into the level of care and support those who care for adults with mental health issues feel that they receive in Shropshire.   The first part examines the efficacy of the carer assessment process and outcomes. South Staffordshire and Shropshire NHS Foundation Trust (SSSFT), now renamed the Midlands Partnership NHS Foundation Trust (MPFT), signed up to the Triangle of Care. The second section of the paper sought to explore how well carers felt its principles had been embedded and practiced by the staff with whom they had come into contact.

Acknowledgements:

Active Carers offer their sincere thanks to all the carers who participated in this project for their openness and support.

This report was compiled by STW Active Carers and written by Marilyn Jones (Chair) in November 2019.

Contents

Section1

Section 2

Introduction

In January 2017 the Centre for Mental Health issued a briefing paper called *Supporting Carers*. The focus was *Mental Health Carers' Assessments in Policy and Practice*[1]. It concluded that mental health carers face unique challenges and further research is essential to embed the Triangle of Care. This project was conceived out of that paper with the specific objective of investigating whether the same or similar situations were reflected in Shropshire and we wish to offer our sincere thanks to Shropshire Healthwatch for funding us to carry out the project.

We therefore set out to explore the following specific areas of enquiry:

- to evidence the usefulness, availability and value of mental health carers' assessments in Shropshire
- to seek variations depending on service or condition
- to gather feedback about how professionals engaged with carers
- to ascertain professional understanding of the role and value of carers' input and their level of understanding of the Triangle of Care (ToC).

Who are we?

STW Active Carers has operated for almost fifteen years across Shropshire and Telford & Wrekin. It is an independent involvement group of lived-experience carers for adults with mental health difficulties. Between our members we have more than 500 years of caring and approximately 100 years of involvement in service provision and delivery as experts by experience. Individual members, in line with their particular areas of expertise and interests, are involved with a wide range of statutory services and voluntary sector organisations at local, regional and national levels. Aiming always to promote the carers' voice in the way adult mental health and social care services are planned, set up and run, Active Carers' members, as experts by experience, have been supporters, advisers, critical friends and thorns-in-the-side to statutory services. From within the group we can evidence pivotal involvement in the introduction, development and training about the Triangle of Care to South Staffordshire and Shropshire NHS Foundation Trust, NHS England's Carers' Voice Network, NHS England's Forensic Carers Toolkit. We are currently co-producing and co-delivering a series of workshops and training sessions on 'Engagement with Carers' with MPFT and are hoping to play a similar role with Shropshire Council's current Carers Support service review.

---

[1] Matthews, K *Supporting carers: Mental health carers' assessments in policy and practice*, Centre for Mental Health, January 2017

Methodology

We decided against creating yet another survey. In order for each carer participant to feel able to express their views and opinions freely, we designed a 2-part questionnaire and spoke to each one face-to-face at a time and place suitable to them. The responses from each are identified only by a reference number. Several participants are carers for more than one adult so additional documents were completed to facilitate the separation of information regarding the different areas of services. All interviews were conducted by mental health carers. Signed consent was received from each participant and an information leaflet and participation letter given. All data used in this report has been anonymised and the source documents and files kept securely by Active Carers.

The first part of the questionnaire concerned Carer Assessments.
The second part related to the Triangle of Care (ToC).

The initial part of each interview established ground-level information detailed below under metadata. The aim was to see if any trends or differences became notable. The fourth of our objectives - around our professional opinions of carers' input and the ToC – has been carried out less formally. The information has been drawn from our work in developing the ToC and Engagement with Carers projects with MPFT. Work is ongoing to introduce the ethos and benefits of ToC to Shropshire Council as part of their current Carer Support Review and other areas.

Rationale

Quite aside from this research project, Active Carers believes that the Triangle of Care needs to be fully embedded in all aspects of adult mental health and social care and support. One key function that would be immeasurably improved by this would be in the carer's assessment. This should open doors and enable practitioners to recognise the value of carers' lived-experience expertise in the needs of their cared-fors. More importantly here, it should give an accurate appreciation of the difficulties faced by the carer in their day-to-day lives. The *Supporting Carers* document concludes that "further research is needed to understand the inequality experienced by mental health carers in terms of assessments … and to make recommendations for improvement". We do not aim to explore this inequality as we have not spoken to any carers of adults with physical health difficulties only or to young carers. We do aim to document the efficacy of mental health carers' assessments carried out in Shropshire.

We believe that there is a need for an evidence-base to provide a benchmark for Shropshire mental health carers that can strengthen the positives and identify the gaps. In turn, we believe, being able to demonstrate meaningful and timely support for these carers will have 2 principal benefits:

- ✓ Unidentified carers will be encouraged to seek effective help and understanding
- ✓ Demonstrate a fiscally responsible approach by early or effective action before matters escalate into requiring more expensive interventions.

The Care Act 2014

The Care Act 2014 came into effect in April 2015 and replaced most previous laws regarding carers and people being cared for. It places new obligations on local authorities and outlines:-

- how local authorities should carry out carer’s needs assessments
- how local authorities should determine who is eligible for support

Details of the provisions and eligibility criteria of the Care Act as they relate to assessments for carers of adults can be found in Appendix 1.

Under the Care Act, in the same way as the person being cared for, all carers are now entitled to a carer’s assessment. They will be entitled to support if they meet the national eligibility criteria. The intent seems to be that this process should be offered by the service provider rather than the carer having to take the initiative themselves. Local authorities are allowed to arrange for other organisations such as charities or private companies to carry out assessments.

The Triangle of Care

The Triangle of Care is defined as a therapeutic alliance between service user, staff member and carer that promotes safety, supports recovery and sustains wellbeing. This joint project between Carers Trust and the National Mental Health Development Unit was launched in July 2010. It emphasizes the need for better local strategic involvement of carers and families in the care planning and treatment of people with mental ill-health. The six standards can be found in Appendix 2.

South Staffordshire and Shropshire Foundation Trust (SSSFT, now part of Midland Partnership Foundation Trust, (MPFT) signed up to the Triangle of Care in 2014.
At that time there was a Section 75 agreement between the council’s Mental Health Social Work Team and the Trust that formally integrated the services and placed the local authority workers under NHS management. In this situation, it is accepted that all staff would be required to adhere to the standards. The Section 75 agreement has since been removed and the team resituated under council management. Shropshire Council is the provider or commissioner of social care support for both carer and cared-for but it has not been possible to establish whether there is any similar framework in place there.

Metadata

We would like it noted at the outset that, despite many requests to all service providers and elsewhere to help us find participants, there was not a single offer resulting. The dataset, therefore, is not quite as substantial as we had planned and, in particular, some geographical areas are particularly under-represented. All participating carers were either already known to us or recommended or introduced by other carers.

Our first tranche of data defined the carers' locations within the county, their age range and sex and how many people they cared for. The aim was to see if any trends around location or condition became evident.

- Our sample found the ratio of female **:** male carers to be 4 **:** 1
- those living in a market town compared to those living rurally 3 **:** 1
- for this analysis we assigned these values to area – Oswestry = 1, Ludlow = 2, Shrewsbury = 3, Market Drayton / Whitchurch / Wem = 4,
  Bridgnorth / Shifnal / Highley = 5
- we interviewed 1 carer under the age of 50 and a found a 49% **:** 51% split of carers aged 50-69 and 70+ respectively
- 35% cared for 1 person; 45% cared for 2 persons; 15% cared for 2 persons, one of which did not have MH issues; 5% cared for 3 people
- Cared-for ages –

Under 18	**18 - 29**	**30 – 49**	**50 – 69**	**70+**
3%	**19%**	**32%**	**23%**	**23%**

- Conditions or diagnoses per the definitions in the Carer Assessment tool –

A	**A/J/F**	**B/C/F**	**B/C/K**	**D**	**D/K**	**F/C**	**F/G/L**	**J**	**K**	**Complex**
43%	**3%**	**7%**	**3%**	**17%**	**3%**	**3%**	**3%**	**3%**	**3%**	**10%**

A = Psychosis, Schizophrenia, Schizo-affective Disorder, Bi-Polar:
B = Depression (all types):
C = Anxiety, Phobias, Panic Attacks, OCD:
D = Dementia (all types):
E = Eating Disorders:
F = Autism:
G = Learning Disabilities:
H = Substance Misuse:
J = Other (including Personality Disorder, Self-Harm):
K = Physical Health (including Parkinson's):
L = Epilepsy
Complex = 3 or more (Active Carers definition)

Section 1 - Carer Assessments

This section explored carers' experiences and their perceptions of carer assessments. Surprisingly, we found 15% had never heard of them. This did not necessarily mean that they had not received any support. We were able to signpost those carers in the right direction and, in one case that we are aware of, the carer found out their cared-for person was eligible for Attendance Allowance. It is not known how long the caring role had been in place without this financial support.

Before we explored assessment experiences, we asked:

What do you understand the assessment to be about?

The majority of respondents had an approximate understanding of the objective itself but there was less appreciation that the assessment was only a first step. Some of the comments suggested:

- the expectation that it would automatically lead to support
- the perception that is purely an information gathering exercise
- only one person mentioned eligibility criteria
- someone believed it automatically led to access to emergency care
- others thought it would lead to financial benefit
- someone had not agreed to an assessment as she understood she was being judged on her ability to be a carer
- it was to establish how much time was involved in their caring role and how much this would affect their ability to work.

There were repeated mentions of sign-posting. We found 72% were neither positive nor negative in their belief that it was about finding out how they were managing in their role and the remaining 28% expressed the view very clearly that it was nothing more than "ticking a box and of no benefit whatsoever".

The next group of questions sought to build a time frame around when, or how, or if, they have ever been offered an assessment. Only 25% of our carers had been offered an assessment within the last 2 years. We then asked this 25% if they had taken up the offer. 60% of them had agreed in principle to taking part in an assessment so we asked how it had been in practice. The great majority stated that it had been a difficult process with the worst case scenario that it only happened following the intervention of the local MP.

We asked those who had not been offered an assessment within the last 2 years when it had last been offered. This produced quite disturbing results - a staggering 45% had never been offered a carer's assessment and of the remaining 55% we found that one had not been offered for:

4 years	5 years	9 years	10+ years
9%	45%	9%	37%

The Carers UK factsheet in Appendix 3 states that the local council should offer an assessment but acknowledges that the carer may have to make the contact themselves. This advice in an England-wide document highlights how common it is for carers to have to initiate the process. It also goes on to say that "the assessment and/or support plan ought to be reviewed every year unless there have been significant changes to the caring role"[2] before then. Our evidence did not find a single instance where this had happened in Shropshire.

Relating to the actual experience of the assessment process, we asked:

1. **Did you feel you were listened to?**
2. **Did you feel comfortable answering their questions?**
3. **Did you feel they understood the mental health condition of your cared-for?**
4. **Did you feel they were trained in that area?**
5. **Would they talk about small details you felt were relevant and important?**

Question	**Very well**	**Fairly well**	**Neither**	**Fairly poor**	**Very poor**
1	**43%**	**36%**	**14%**	**0%**	**7%**
2	**57%**	**29%**	**7%**	**0%**	**7%**
3	**43%**	**29%**	**7%**	**0%**	**21%**
4	**36%**	**21%**	**21%**	**7%**	**14%**
5	**57%**	**14%**	**21%**	**7%**	

These responses reflect generally positive perceptions of experiences with little that was non-committal. The notable exception was in question 4 around the perceived level of staff training. This opened another question which we did not consider until we analysed the results – Were the assessments carried out by the Mental Health Social Work Team or the generic team? Logically, this last should not be the case as it would defeat some of the *raison d'etre* for creating the specialised team. We do, however, know that the generic team has/does carry out assessments on carers of adults with mental health difficulties but we do not know if this applied in any of our subject group. This is perhaps a question for further enquiry.

Using these responses, we next enquired about the results and/or support that came from the assessment process. Only slightly over half of the participants believed that their information was accurately recorded. This may be partially explained by the fact that fewer than half of them received a copy of the paperwork. This contributed to a general sense of dis-satisfaction with the process:

- for some it reinforced the feelings that they had not really been listened to
- for others that they had nothing to refer back to if help was not forthcoming.

---

[2] Carers UK Factsheet E1020_1118 – Assessments, For Adult Carers, pp2-8, Appendix 3 Factsheet Stage 2

Whether or not a local authority decides that a carer has eligible needs, they have a duty to inform the carer in writing[3]. Without a copy of the assessment paperwork the carer has no basis to pursue the decision.

Although it was not a specific question, it was made very clear by the carers who had been in their role for some time that they noted a definite deterioration in the whole process from what it had been "under the 'old' system". This relates to when Shropshire RCC had the contract for all aspects of carer support - when carer support professionals had their specialism, undertook the carer assessment and followed that up with the support. The change bringing carer assessments in-house with the council and carer support being contracted to CarersTrust4All has brought about two points of note. With no reflection on any of the service providers, carers felt that:

- communication had become disjointed and much more difficult
- in the change to carer support workers becoming generic instead of specialism-based, much knowledge has been lost or become much more difficult to find.

There is further comment about this further on.

Wellbeing and Significance

These two terms appear in both the legislative document and the Carers UK factsheet

> *'Wellbeing' is defined in the Care Act but the definition is very broad and includes things like social and economic wellbeing, personal dignity, control over your day-to-day life, participation in education, work or social activities, relationships with other people, having suitable accommodation, protection from abuse and neglect.*
>
> *'Significant' is not defined in law, and so should be given its everyday normal meaning. If you think the effect on you is noticeable or important, this could count as significant."*[4]

We do not believe our carers felt that their wellbeing received the attention it warranted. Although there was evidence of understanding how the carer was feeling, there was not much offered to support it. A number of the aids that were offered were of a more practical nature. While these were welcome, they tended to benefit the cared-for's day-to-day living directly and, therefore, were more of an indirect support for the carer rather than the psychological or emotional support that was needed. One of the key points in the Act is to ensure that the needs of the carer and the cared-for are balanced. Overall, we did not feel this aim was met.

Within this project, significance is extremely important. It is personal and subjective. It relies on the assessor's understanding and preparedness to acknowledge that it is the carer who knows best exactly how they are feeling and coping. The carer is usually the one who recognises the things that have a serious impact on their wellbeing. Needs, therefore, should be based on the carer's circumstances not the assessor's assumptions.

---

[3] https://www.carersuk.org/help-and-advice/practical-support/getting-care-and-support/carers-assessment#contenttop,Factsheet E1020_1118 – Assessments,p7

[4] Carers UK Factsheet E1020_1118 – Assessments, For Adult Carers, pp2-8

Variations in the appearance of need are common. The cared-for's behaviour from day-to-day or week-to-week are perhaps less than fully considered. There are a number of mental health conditions and co-morbidities that can and do fluctuate in very pronounced ways. In the midst of that, the carer may well be trying to juggle other responsibilities like children, work or running a household. The reason is less important than the whole situation. Unfortunately, we are aware there is a long history of services commissioning and providing what **they** think carers want and need. Across the board, our carers showed us that these could be taken into account more fully and there is work to be done for these objectives to be achieved.

All the comments around experience were combined as respondents found it easier to answer. Generally, people did feel listened to. From our experience we know that for many carers this, in itself, is gratifying and, for some, perhaps even an unfamiliar occurrence. However, although the percentages do not exactly reflect it, carers clearly felt that they were understood much better where the assessor had a specific mental health background and much less confidence where the assessor did not. A few felt that, despite giving some appearance of understanding, these were sometimes a little deceptive and this brought about impressions that the exercise was a waste of time.

Some concern was also expressed that because it is only on very rare occasions that the assessor has met the cared-for, there was less understanding of some aspects of their presentation. While the assessment is directed towards the carer's needs, this missing piece does have a crucial bearing on the physical and mental wellbeing of the carer, both at the appointment and in their everyday lives.

Consideration needs to be given to how comfortable, willing or able the carer is to admit or discuss some of their deepest issues especially if the cared-for is also present. Although no-one we interviewed said they felt judged, there is frequently a feeling that such admissions reveal their failures, inadequacies and sometimes their guilt about how they feel about their roles.

Both the legislation and the Carers UK factsheet (Appendices 2 and 3) make it very clear that the local council must provide the carer with an independent advocate[5] during and after the assessment if the carer feels unable to communicate effectively or retain any information given. We did not find one carer who was aware of this additional support even among those who had found the process difficult. This gives added import to the earlier finding that less than half of those who had had an assessment actually received a copy of it.

A few noted that actual support, primarily sign-posting and counselling for themselves, did result from their assessment. The most helpful benefits were help with getting a diagnosis, housing support and day-care sessions – all for the cared-for not the carer. While all of these do unquestionably alleviate some of the stresses of caring, and while any help is appreciated, these are all indirect benefits to the carer.

---

[5] See the last paragraph of Stage 1 in Appendix 3

This validates an opinion widely reported by carers that if services supported their cared-fors better or more appropriately there would be less call for the carers themselves to be in need of help.

There were fairly widespread negative comments that either:

- nothing had been forthcoming as there was nothing out there or
- what was on offer was inappropriate and unsuitable for their needs.

One example given was that of a ‘Pamper Session’. This along with coffee mornings and walking groups is not what many carers are seeking by way of support. Other references were made to the lack of specialism that was available for certain conditions or situations:

- around bereavement and end-of-life caring
- lack of support for Autism and that Shropshire and Telford Asperger Carer Support (STACS) was their only support
- despite being given hope that specialist support would be given from the Memory Clinic and the Alzheimer’s Society. Unfortunately, this promise has been marred by the failure of services to arrange this follow-up.

The opinion was commonly expressed that specialist support relating firstly to mental health conditions, certain co-morbid conditions and palliative caring, for example, was much to be preferred and needed. This selection of comments highlights the effects if the assessor’s experience on the process:

- had experience because of being a Mental Health Support Worker
- was knowledgeable about the condition …and was a trained MH worker
- everything was being put down as bereavement issues
- hadn't got insight and detail.
- wasn't sure they understood SU's difficulties

Have you continued to access support?

This question brought a very mixed range of responses. Aside from one carer who felt that they were currently able to cope without it, one who declined because they felt it was not sufficiently specific, one where the cared-for had needed to move into full-time care and one exception where the carer had been offered time-limited support from Mental Health Services, any support that was being accessed was offered through the voluntary sector or friends and family as per these comments:

- Support only from family and friends. No other help
- family are able to provide respite

Reference was made to the feeling of security felt by the carer when family offered them respite. This highlighted the difficultly often felt by carers whose lives had become hugely affected by the time and level of care that had become required – uncertainty that professional carers would understand and provide what the family member felt was needed. Although there was very little in our collected evidence to validate this, it would not be unreasonable to deduce that there are many carers who struggle to trust external care-providers irrespective of how this may be damaging their own wellbeing. This almost inevitably leads to the carer giving up their own social and work activities and has the knock-on effect of increasing isolation and affecting finances.

Rethink and the Alzheimer’s Society were given as sources of support. However, there were a few less than positive comments around the ability to access the latter. This was somewhat offset by the mention of the Alzheimer’s buddy scheme for carers. We were told that one voluntary sector organisation that had been used previously no longer offered carer support; POHwer did not offer support suitable to the carer needs. These negative comments point to a lack of follow-up post-assessment to establish whether suggestions had been followed, were still on offer or were appropriate. These gaps tend to strengthen beliefs that the assessment is a box-ticking exercise which can lead to the carer feeling ‘out of sight – out of mind’.

The all-round conclusion drawn here is that little on-going support was available from statutory-commissioned services and not too much of that was easily accessible. There is, perhaps, a question here regarding signposting to voluntary sector organisations with regard to their capacity. Family and friends continue to play a huge role.

Section 2 – The Triangle of Care

Membership of the Triangle of Care brings with it the right to display the logo on all internal and external documentation. It is a declaration that the organisation recognises not only the value of the role carers can play in the patient's journey but also acknowledges the physical and emotional difficulties caring entails. Compliance with the principles of ToC implies that there are support processes in place. There had been no formal staff training in ToC within the Trust at the time we started this project and very little in the interim. In our interactions with the organisation we had found staff had little knowledge of it. This section of the project aimed to explore whether the principles were being adhered to as normal practice irrespective of the formal recognition of ToC standards - see Appendix 2.

We found that 75% of our carers had heard of the Triangle of Care before they commenced their interview with us. This is testament to the ongoing efforts by a number of informed carers and service users to cascade information about it at every opportunity and over a number of years. Although not formally evidenced, this may well have exceeded the staff percentage at the start of the project. Since then, many more members of staff have become much more aware of ToC.

The table below represents what information we collected regarding how carers were treated by staff, especially on first contact. The descriptors follow the spirit of ToC standards if not the exact wordings. Any responses in the 'Sometimes' column either reflect which strand of mental health services the cared-for was in, or where the carer supported more than 1 person, or the reactions of different staff members with whom they had contact. The 'Don't knows' reflect the carers' state of mind and focus, especially in the very emotional position they find themselves in at in-patient admissions.

		Yes	No	Some times	Don't know
Std 1	**Were you identified as a Carer?**	**67%**	**19%**	**5%**	**10%**
	Was your role acknowledged?	**62%**	**24%**	**10%**	**5%**
Std 2	**Were staff Carer Aware/Trained?**	**29%**	**38%**	**19%**	**14%**
Std 3	**Were you told why some info not shared?**	**81%**	**19%**		
	Were you given any other information?	**38%**	**43%**	**5%**	**14%**
Std 4	**Was there a named Carers Lead?**	**10%**	**90%**		
	Any other staff?	**48%**	**29%**	**14%**	**10%**
Std 5	**Were you given Info pack on 1st contact?**	**14%**	**86%**		
	Were you given Info at any other time?	**71%**	**29%**		
Std 6	**Were you told about a range of support?**	**24%**	**76%**		
	Were you told of your Right to a Carer Assessment?	**24%**	**71%**		**5%**

The table above is a purely numerical illustration of ToC as carers perceived it. We have not analysed responses based on the cared-fors' diagnoses at this time. That may have been able to show a correlation between the branch of services and their use of ToC but we felt that our data lacked the specificity to be able to report this with certainty. There is a much more detailed body of evidence and opinion to follow. The numbers indicate disappointingly low results across the board.

- **Standard 1** - only 2 out of 3 carers were identified and felt valued.
- **Standard 2** - less than one third of staff demonstrated the carer awareness called for.
- **Standard 3** - issues around confidentiality were dealt with much better but the sharing of related information showed results that are decidedly below the halfway point and therefore require significant improvement.
- **Standard 4** - there is very little evidence of a named Carers' Lead in any area.
- **Standard 5** - fewer than half of all staff encountered offered support to carers.
- **Standard 6** – almost 4 out of 5 carers were not advised of the range of support on offer or of their right to a carer's assessment

Despite numerous assertions and promises, there exists little sign of Carer Information Packs. We believe the markedly higher figure for information on subsequent contact may relate to those whose cared-for was in the Older Adult Wards at The Redwoods or the Memory Service. A staggering three quarters of carers were not advised of any available support or of their right to a carer assessment. Active Carers believes, and the Care Act 2014 appears to suggest, that finding out about these things should not fall to the carer's ability to navigate the complexities of mental health and adult social care service provision without guidance. After all, the legal right to an assessment is meaningless unless the carer is aware of it and able to access it. The second part of Standard 5 revealed a very wide and informative range of sources of information and how they were found. This, to a large degree, pays testament to the quality and resourcefulness of Shropshire Mental Health Carers themselves. Some extracts, positive and negative, are included below:

- Information was self-sought
- Royal College of Psychiatrists; Mental Health Act; Government site; Royal College of Nursing; DWP website
- Rethink; Academic papers on research via the web
- From Active Carers, Rethink, Carers Trust 4 All groups
- IAPT; Family therapy (E/I); information sessions at Severnfields (E/I)
- Meeting other carers and sharing
- Being able to talk about it is the best remedy for me
- Just support from carer friend / Fellow carer has been helpful
- Alzheimer's pack from social services
- Open door policy, so can call the memory clinic any time
- Written information comes to cared-for […] No contact or information to me personally
- Attendance Allowance and Emergency respite from Carers Trust 4 All
- In-patient staff eventually found some information to give me.
- Community worker just comes to see cared for person
- From Carers Trust 4 All just about social group trips.

The scope of these comments indicates that the majority of helpful information and support carers found came from other carers and voluntary groups. The charity, CarersTrust4All, is a commissioned service and there is evidence here that it has given more factual information than personal support.

There are references above, relevant although slightly out of place, that carers are not automatically included in the development of care or discharge plans and that they do not receive attention or information in their own right. This would appear to indicate that some changes in thinking processes are called for to comply with ToC standards.

Our evidence shows that, in addition to the dishearteningly low figures of less than two thirds of carers being identified and valued, there was markedly even less attention than that given to communicating with carers about their legal and statutory rights.

As in any organisation, there are pockets of 'good practice' and these were clearly recognised and appreciated by the carers who were fortunate(?) enough to find themselves in those pockets. Overall however, our carers' practical experiences of how well staff who were supposedly applying ToC standards, listened to, valued and helped carers were negative across the board. Our carers reported a mixture of anger, frustration, cynicism and hopelessness. These feelings have been highlighting using some extracts from their comments:

Anger:

- I do not understand the need for 'confidentiality'. Do not think staff are sufficiently trained to understand relationships. Use 'confidentiality' as a barrier.
- They just talk to my cared-for person and I am left to sit separately
- Have not had any contact about changes to our son's care plan (even though he has given permission)
- Care co-ordinator has changed twice (between July and November). No contact and no information on 'Pathway' changes

These carers are clearly involved. Confidentiality appears to be a compelling area of staff concern. They seem to lack the confidence of knowing what information they should or could pass on. Carers frequently have an integral role in the cared-for's life – they may live in the same home, oversee the taking of medication or need to arrange the attendance at appointments. Carers are demonstrably part of the care/discharge plans and patient journeys. As such, they have a right to be included in the development and practice of these plans. In our experience, most carers do not want to know every detail. They want to know the practical things like when medication is to be taken and when appointments are. In addition, information and support around how to manage some aspects of the cared-for's condition are found to be extremely helpful. There is clearly a training gap around the definition and boundaries of confidentiality.

Frustration:

- Took a long time to get to being taken seriously; SU able to 'mask' symptoms very well
- All the time you have to push for involvement. Cared for person may have distorted views when ill
- Please talk to the carers; please keep them involved - don't treat them like they don't exist

It is apparent from these comments that many staff fail to recognise that the carer knows the patient far better than they do. As well as being frustrating for the carer, this disregard for the value of the carer perspective can have a seriously limiting effect on treatment planning as many aspects of their cared-for's presentation may be masked and triggers may not be noticeable. This demonstrates a need for training around 'Engagement with Carers'.

Cynicism:

- I feel standards of care are used as propaganda on authorities' websites and don't translate into everyday situations
- Staff at St George's seemed better trained to engage with carers than at Redwoods
- Mental health and substance misuse services each use the other as a cop out.

These comments are patently from experienced carers who have had long term interaction with mental health services. There would seem to be informed expectation that a signatory to ToC should be living up to the standards more effectively. There may also be an implied willingness to support services to 'get it right'! Staff training to ingrain a culture of carer awareness could be facilitated by carers such as these to everyone's benefit.

Hopelessness:

- You don't know where you are - need consistency of care
- When it is very new to you, you don't know what questions to ask. It can be as traumatic to you as to the person with the MH problem
- The most difficult thing for me is understanding who does what - the roles, and who has all the information

In contrast to the previous points that focus more on the practical or functional, these highlight the emotional cost and strain of being or becoming a mental health carer. Understanding is the key. Much more needs to be done to support carers, alleviate their concerns and help them look after their own wellbeing. Guidance to navigate complex statutory systems is necessary. Again, the evidence demonstrates that training on 'Engagement with Carers' is called for.

Other noteworthy points

- It was noted by one carer that the police were "helpful, understanding and treated me as a carer". It is not known if this was a pointed comment to contrast with MH staff
- A number of comments were poignantly made about the very poor treatment and recognition of carers when the cared-for was in a care home. Where our relatively small sample of evidence has uncovered these poor practices, it is not unreasonable to deduce that they also exist for the many more carers we did not talk to. Disturbing as this is, very few if any care homes are signed up to the Triangle of Care and therefore analysis or further investigation falls outside the scope of this project
- Substance Misuse Services do not understand dual diagnosis. They don't understand the difference between recoverable and enduring MH conditions. The converse also applies to Mental Health staff .

To summarize briefly – our results evidence a lack of policy, process and/or staff training, ability or willingness that would be commensurate with a fully embedded Triangle of Care.

NEED TO DO BETTER!

A Final Round-Up of general comments predictably yielded a wide variety of observations.

The majority related to emotional elements of the carer's day-to-day struggles:

- Little understanding of the mental stress caused to MH carers by both the lack of support and of relevantly-trained staff
- Don't feel supported by MH Trust; experience isn't valued by some staff; they can be very dismissive
- Some don't realise the impact that enduring MH conditions have on a family - emotionally, physically and financially
- Think I was lucky, getting the help I got
- I would like to think that there is someone to ring or contact when things get too much
- Need this level of support to continue as uncertain future
- Carers should have regular physical and mental health checks
- Staff do not value carers or understand the constant pressure; carers do MH services' job
- Role of the carer is under-acknowledged. I am not convinced Social Workers are au fait with MH issues

All of these were very succinctly expressed by two carers –

"Just coping!" "We all look after each other"

Assessments should not be offered on just one occasion. They should be offered again if declined first time, perhaps at a less stressful time for the carer.

Triangle of Care has been a massive improvement but there is still a need to ensure the Trust is doing it properly as some staff members still do not automatically implement the 3rd part in the Triangle – the carers.

Concerns around diagnosis and processes: –

- Co-morbid conditions are sometimes not fully identified and assessed - yet this can have a huge impact
- Staff do not always accept responsibility or duty of care. This is why there is frequently a merry-go-round between all services
- RSH treatment of MH patients with problems of a physical nature

Confidentiality:

- Can be a barrier to supporting. Professionals make assumptions about the carer's understanding of situations and MH issues
- Issues with all services - will not talk to me, and cared for person will not talk to make appointments
- There is confusion between 'carers' who are paid staff and unpaid family carers.

Autism:

- Staff need to be better trained to understand the complexities of autism
- There is valid thinking that anyone going into services with autism, or potential autism, should go onto the Intensive Life Skills pathway or other complex care option for initial assessment of need

Finally:

To mitigate the negativity of the previous pages, one carer commented:

"I have been so pleased with the services and support here in Shropshire."

Conclusion

The evidence found an overall negative view of carer assessments - a data collection exercise that brought little benefit. 75% had not been offered one in the last 2 years and almost half of that group had never been offered one.

The experience of the assessment informed us that carers found it very much better when the assessor was a mental health professional. However, many noted poor follow-up and lack of specialism.

Our carers found there was reasonable practical support but little emotional support. What ongoing support was available was mostly found in the 3rd sector, was often generic and not what was wanted or needed.

The ethos of the ToC was found to be inadequately practiced overall. Carers were frequently ignored, excluded or not supported. There are significant issues around confidentiality.

Recommendations:

1) Assessment and ongoing support from a specialist mental health team should be offered to every mental health carer and re-offered at a later date, if not taken up at first. Paperwork and dates should be logged for review purposes and to comply with statutory requirements.
2) Ongoing practical support around finance / housing etc. should be delivered by the same specialist team to remove the existing gap.
3) Carers found generic support unsatisfactory. Commissioners need to listen to what carers actually want and need and commission voluntary organisations to offer that accessible emotional and person-centred support.
4) Emotional support should be delivered by a range of mental health specialists from both the MH social work team and the voluntary sector.
5) Specialist support is required around certain conditions, eg autism, to comply with statutory guidelines.
6) ToC training is needed for all mental health staff, should be mandatory and should also be offered to all carer-facing staff.
7) Carer information packs or leaflets and carer lead need to be in place. Carers should be informed of any changes in service that impact on them.

Overall, our evidence corroborated the conclusion of the Centre for Mental Health's paper and confirmed that it also held true for Shropshire – namely that mental health carers do face unique and difficult challenges that are largely unrecognised and unsupported.

The evidence also revealed that much more effort is essential to embed the Triangle of Care within mental health services.

Unpaid carers provide huge savings in terms of all resources.
They need to be treated as individuals in their own rights, not add-ons,
and they certainly deserve better than is currently available.

Appendix 1 - Sections from The Care Act 2014

http://www.legislation.gov.uk/ukpga/2014/23/section/10/enacted

Section 10 - Assessment of a carer's needs for support

(1) Where it appears to a local authority that a carer may have needs for support (whether currently or in the future), the authority must assess —

(a) whether the carer does have needs for support (or is likely to do so in the future), and

(b) if the carer does, what those needs are (or are likely to be in the future).

(2) An assessment under subsection (1) is referred to in this Part as a "carer's assessment".

(3) "Carer" means an adult who provides or intends to provide care for another adult (an "adult needing care"); but see subsections (9) and (10).

(4) The duty to carry out a carer's assessment applies regardless of the authority's view of —

(a) the level of the carer's needs for support, or

(b) the level of the carer's financial resources or of those of the adult needing care.

(5) A carer's assessment must include an assessment of —

(a) whether the carer is able, and is likely to continue to be able, to provide care for the adult needing care

(b) whether the carer is willing, and is likely to continue to be willing, to do so,

(c) the impact of the carer's needs for support on the matters specified in section 1(2),

(d) the outcomes that the carer wishes to achieve in day-to-day life, and

(e) whether, and if so to what extent, the provision of support could contribute to the achievement of those outcomes.

(6) A local authority, in carrying out a carer's assessment, must have regard to —

(a) whether the carer works or wishes to do so, and

(b) whether the carer is participating in or wishes to participate in education, training or recreation.

(7) A local authority, in carrying out a carer's assessment, must involve —

(a) the carer, and **(b)** any person whom the carer asks the authority to involve.

(8) When carrying out a carer's assessment, a local authority must also consider —

(a) whether, and if so to what extent, matters other than the provision of support could contribute to the achievement of the outcomes that the carer wishes to achieve in day-to-day life, and

(b) whether the carer would benefit from the provision of anything under section 2 or 4 or of anything which might be available in the community.

(9) An adult is not to be regarded as a carer if the adult provides or intends to provide care -

(a) under or by virtue of a contract, or **(b)** as voluntary work.

(10) But in a case where the local authority considers that the relationship between the adult needing care and the adult providing or intending to provide care is such that it would be appropriate for the latter to be regarded as a carer, that adult is to be regarded as such (and subsection (9) is therefore to be ignored in that case).

(11) The references in this section to providing care include a reference to providing practical or emotional support.

(12) This section is subject to section 11(5) to (7) (refusal by carer of assessment).

Section 13 - Refusal of assessment

(1) Where an adult refuses a needs assessment, the local authority concerned is not required to carry out the assessment (and section 9(1) does not apply in the adult's case).

(2) But the local authority may not rely on subsection (1) (and so must carry out a needs assessment) if –

(a) the adult lacks capacity to refuse the assessment and the authority is satisfied that carrying out the assessment would be in the adult's best interests, or
(b) the adult is experiencing, or is at risk of, abuse or neglect.
(3) Where, having refused a needs assessment, an adult then requests the assessment, section 9(1) applies in the adult's case (and subsection (1) above does not).
(4) Where an adult has refused a needs assessment and the local authority concerned thinks that the adult's needs or circumstances have changed, section 9(1) applies in the adult's case (but subject to further refusal as mentioned in subsection (1) above).
(5) Where a carer refuses a carer's assessment, the local authority concerned is not required to carry out the assessment (and section 10(1) does not apply in the carer's case).
(6) Where, having refused a carer's assessment, a carer requests the assessment, section 10(1) applies in the carer's case (and subsection (5) above does not).
(7) Where a carer has refused a carer's assessment and the local authority concerned thinks that the needs or circumstances of the carer or the adult needing care have changed, section 10(1) applies in the carer's case (but subject to further refusal as mentioned in subsection (5) above).

Section 13 - The eligibility criteria

(1) Where a local authority is satisfied on the basis of a needs or carer's assessment that an adult has needs for care and support or that a carer has needs for support, it must determine whether any of the needs meet the eligibility criteria (see subsection (7)).
(2) Having made a determination under subsection (1), the local authority must give the adult concerned a written record of the determination and the reasons for it.
(3) Where at least some of an adult's needs for care and support meet the eligibility criteria, the local authority must—
(a) consider what could be done to meet those needs that do,
(b) ascertain whether the adult wants to have those needs met by the local authority in accordance with this Part, and
(c) establish whether the adult is ordinarily resident in the local authority's area.
(4) Where at least some of a carer's needs for support meet the eligibility criteria, the local authority must -
(a) consider what could be done to meet those needs that do, and
(b) establish whether the adult needing care is ordinarily resident in the local authority's area.
(5) Where none of the needs of the adult concerned meet the eligibility criteria, the local authority must give him or her written advice and information about —
(a) what can be done to meet or reduce the needs.
(b) what can be done to prevent or delay the development of needs for care and support, or the development of needs for support, in the future.
(6) Regulations may make provision about the making of the determination under subsection (1).
(7) Needs meet the eligibility criteria if —
(a) they are of a description specified in regulations, or
(b)they form part of a combination of needs of a description so specified.
(8) The regulations may, in particular, describe needs by reference to —
(a) the effect that the needs have on the adult concerned; **(b)** the adult's circumstances

http://www.legislation.gov.uk/ukpga/2014/23/section/10/enacted

Appendix 2 - The Triangle of Care Standards

Standard 1

Carers and the essential role they play are identified at first contact or as soon as possible thereafter

Standard 2

Staff are ‘carer aware’ and trained in carer engagement strategies

Standard 3

Policy and Practice Protocols re: confidentiality and sharing information are in place

Standard 4

Defined post(s) responsible for Carers are in place

Standard 5

A Carer introduction to the service and staff is available

Standard 6

A range of Carer support services is available

Appendix 3 - Carers UK Factsheet E1020_1118 – Assessments

Chapter 7 For adult carers

Stage 1: Assessing your support needs

What is a carer's assessment? Page 2

A carer's assessment is for carers over 18 years old who are looking after another adult over 18 years old who is disabled, ill or elderly. It is an opportunity to record the impact caring has on your life and what support or services you need. The assessment will look at for example, physical, mental and emotional needs, and whether you are able or willing to carry on caring.

Who can have a carer's assessment?

Any carer who appears to have needs for support can have an assessment by the local council.

As a carer you will be entitled to an assessment regardless of the amount or type of care you provide, your financial means or your level of need for support. You can have an assessment whether or not the person you care for has had a needs assessment, or if the local council have decided they are not eligible for support. If you and the person you care for agree, a combined assessment of both your needs can be undertaken at the same time. If you are sharing caring responsibilities with another person, or more than one person, including a child under 18, you can each have a carer's assessment. You don't necessarily have to live with the person you are looking after or be caring full-time to have a carer's assessment. You may be juggling work and care and this is having a big impact on your life.

How do you get a carer's assessment?

As a carer you should be offered an assessment by the local council adult social services department of the person you care for. If you have not been offered one, you should contact them by phone, in writing or on-line, and ask for a carer's assessment or for a review of your support plan (if it has been a year since your last one, or less than a year but your circumstances have changed). If you want to, you can ask for an assessment before you take up your caring role.

How do you prepare for a carer's assessment? Page 3

In preparation for your assessment, it is useful to give yourself some time to think about how caring affects you. It's also important to start thinking about any help that would make a difference to you as a carer. This will help when you discuss things that the local council have to consider when doing a carer's assessment. For a list of questions which should give you a clear idea of the help you may need, see the appendix on page 28. (NB Not included here)

Bear in mind that you might not know about all the types of help that could be available, the assessment is to help the local council understand what things you are having problems with. The local council must give you information about the assessment in advance – for example a list of the questions they will ask.

They may give you a form to write down your thoughts to these questions before the carer's assessment. Often this is referred to as a self-assessment questionnaire.

Alternatively you may find it helpful to write some notes for yourself, and talk to family or friends to help you think about your needs.

How is a carer's assessment carried out?

The law says that all assessments must be carried out in a manner that:

- is appropriate and proportionate to your needs and circumstances
- ensures that you are able to participate effectively in the assessment
- has regard to your choices, wishes and the outcomes you want to achieve
- takes account of the level and severity of your needs

In some areas local organisations, such as carers' organisations, may be asked to carry out the assessment. Your rights remain the same in this situation, and the local council still has the ultimate responsibility for any decisions made. If the assessment involves a meeting, it should be carried out in a convenient and private place. Meetings are likely to be part of the process if the person you care for is having an assessment as well. It is your choice whether the person you care for is present or not.

If it helps, you can have a family member, a friend or a Carer Support Worker from a carers' organisation with you.

Assessments can be done over the phone or online, but this should only happen if you agree. If you think you can easily express your needs over the phone or online then this method may be the right one for you. Online or telephone assessments are unlikely to ever be appropriate for people who lack capacity or have difficulties with communication. The local council may carry out a supported self-assessment. This could involve you filling in a self-assessment questionnaire, and then being contacted by the local council to discuss what you have written on the form.

The assessment will consider whether or not your caring role impacts on your health or prevents you from achieving outcomes, for example staying in work or having a social life, and what could be done to help you combine these things with caring. It should cover:

- your caring role and how it affects your life and wellbeing
- your health – physical, mental and emotional issues
- your feelings and choices about caring
- work, study, training, leisure
- relationships, social activities and your goals
- housing
- planning for emergencies (such as a Carer Emergency Scheme) – the local council should be able to tell you more about what they can do to help you plan for an emergency.

You should be asked about these issues, if not you can raise them yourself. The aim of the assessment is to help you get the support that you need. So it's best to give your honest opinion about your caring role, the care you provide and your feelings about being a carer. Remember to look at the list of questions in the appendix on page 28 of this factsheet. (NB Not included here)

Independent advocate

The local council must provide you with an independent advocate to assist you in the assessment process (and after) if:

- without support you would have ‘substantial difficulty’ in communicating your wishes, or understanding, retaining and assessing information during the assessment and
- there is no other appropriate person who is able and willing to help you.

Stage 2 – Looking at whether your needs are eligible for support

How will the local council decide if my needs as a carer are eligible for their support?

The Care Act introduces national rules for deciding who is eligible for care and support. But it will still be for local councils to make the decision about whether or not your needs meet the rules and so whether you have what the law calls eligible needs. You will meet the eligibility criteria if there is likely to be a significant impact on your wellbeing as a result of your caring role. There are three questions the local council will have to consider in making their decision:

- Are your needs the result of you providing necessary care?
- Does your caring role have an effect on you?
- Is there, or is there likely to be, a significant impact on your wellbeing?

If the answer to all three questions is yes, then you will have eligible needs. These questions are explained in more detail below.

Are your needs the result of you providing necessary care?

The local council could decide that the care you provide is not necessary, that the cared for person could do the things you do themselves. Or they could decide that your needs or problems are the result of something other than your caring role.

Does your caring role have an effect on you?

The effect on you must be either:

- your physical or mental health is at risk of getting worse, or
- you are unable to achieve at least one of the following outcomes:
  - look after any children you have responsibilities for
  - provide care to any other person
  - maintain your home in a fit and proper state
  - eat properly and maintain proper nutrition
  - maintain and develop your relationships with family and friends
  - take part in any education, training, work or volunteering you wish to
  - time for social activities, hobbies etc.

In considering whether or not you can achieve the above outcomes, the law states that the local council must take into account any difficulties you have. You will be considered unable to achieve the outcome if you:

- need assistance to achieve the outcome
- can achieve the outcome unaided but experience significant pain, distress or anxiety
- can achieve the outcome unaided but doing so endangers, or may endanger your or another person’s health and safety

Is there, or is there likely to be, a significant impact on your wellbeing?

‘Wellbeing’ is defined in the Care Act. The definition is very broad and includes things like social and economic wellbeing, personal dignity, control over your day-to-day life, participation in education, work or social activities, relationships with other people, having suitable accommodation, protection from abuse and neglect. ‘Significant’ is not defined in law, and so should be given its everyday normal meaning. If you think the effect on you is noticeable or important, this could count as significant. Although the Care Act does not define what counts as a significant impact on your wellbeing, it does list a number of things that the local council must take into account when considering the issue. These are:

- you are best-placed to judge your wellbeing
- your views, wishes, feelings and beliefs should be considered
- the importance of reducing existing needs, and preventing or delaying the development of needs
- decisions should be based on your circumstances, not assumptions about you
- you should be able to participate as fully as possible in decision making **Page 7**
- the needs of the carer and cared for person need to be balanced
- the need to protect people from abuse and neglect
- any restrictions on rights or freedoms should be kept to the minimum possible.

If your level of need varies, the local council must take this into consideration to gain a full picture of your level of need.

The reason for the variation is not important; it can be because the condition of the person you care for fluctuates from day to day or week to week, or because you have other responsibilities that can affect you from time to time.

Stage 3 - What help you might get after a decision about your needs

If you don't have eligible needs

If the local council decides that you do not have eligible needs, then you must be given a written decision explaining this. You must also be given advice and information about what could be done to prevent or reduce your needs either now or in the future. This advice and information should be based on your specific circumstances.

If you do have eligible needs

If the local council decides that you do have eligible needs, then providing you want them to, they have a legal obligation to meet these needs and must draw up a support plan detailing how these needs will be met. It may be agreed that the best way to help you as a carer is by providing services directly to you, by providing services to the person you care for, or a combination of both.

The local council can provide services themselves, or arrange services through another organisation. Alternatively, you or the person you care for can request direct payments, which are payments which enable you to buy services to meet your eligible needs. For more information on direct payments visit carersuk.org/directpayments .The local council may or may not charge you for carers support, most councils do not. If they do, they must carry out a financial assessment to work out whether you have to make a contribution and if so, how much. If the help you are offered is free, the local council do not have to carry out a financial assessment. **Page 8**

Note: If the local council do charge for carers support and the outcome of your financial assessment is that you will have to pay the full charge, then the local council only has to meet your needs and draw up a support plan if you ask them too. The local council can then issue an additional charge for this.

The support plan must include:

- details of the needs identified in the assessment
- which needs meet the eligibility criteria
- which needs the local council is going to meet, and how the outcomes that you want to achieve
- information about the personal budget available (the amount of money that the local council has worked out it will cost to arrange the necessary support for you)
- information about direct payments
- information and advice to support you in your role as a carer and address your needs.

Some examples of the kind of help that could be available to you as a carer if you are eligible for support:

- help with transport costs, such as taxi fares or driving lessons
- costs for a car where transport is crucial, such as repairs and insurance
- technology to support you, such as a mobile phone or a computer where it is not possible to access computer services elsewhere
- help with housework or gardening
- help to relieve stress, improve health and promote wellbeing such as gym membership.

Some examples of the kind of help that could be available to the person you care for, in order to help you as a carer:

- changes to their home to make it more suitable equipment such as a hoist or grab rail
- a care worker to help provide personal care at home
- a temporary stay in residential care/respite care meals delivered to their home
- a place at a day centre
- assistance with travel, for example to get to a day centre
- laundry services
- replacement care so you can have a break.

References

1. Matthews, K Supporting carers: Mental health carers' assessments in policy and practice, Centre for Mental Health, January 2017, January 2017
2. www.legislation.gov.uk/ukpga/2014/23/section/10/enacted, accessed 11/10/2019
3. http://www.legislation.gov.uk/ukpga/2014/23/section/11/enacted, accessed 11/10/2019
4. http://www.legislation.gov.uk/ukpga/2014/23/section/13/enacted, accessed 11/10/2019
5. Carers UK Factsheet E1020_1118 – Assessments, For Adult Carers, pp2-8 downloaded from www.carersuk.org.uk on11/10/2019