Consultation Report:

Support Services for Mental Health Carers in Oxfordshire

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1. About Us

1.1 The NHS Buckinghamshire and Oxfordshire Cluster

NHS Buckinghamshire and NHS Oxfordshire have now become joined or ‘Clustered’.

NHS Clusters have been established by the Department of Health to ensure that the NHS maintains business continuity of commissioning healthcare locally and to facilitate the change to the new structure of the NHS in 2013, including the move to Clinical Commissioning Groups (CCGs)

All NHS Clusters will have three principal functions:

- Delivery of the PCTs’ Operational Plans and driving clinical service change for 2011 to 2013 and ensuring financial stability for the handover to Clinical Commissioning Groups
- Ensuring and supporting development of Clinical Commissioning Groups and transferring of other current cluster functions to the new organisations yet to be established i.e. the National Commissioning Board, Public Health England, Health Education England, Health and Wellbeing Boards, public health to Local Authorities
- Creating the relevant commissioning support organisation for Clinical Commissioning Groups after post PCT abolition.

1.2 About Oxfordshire

We are ambitious about improving the health and wellbeing of local people. The NHS Oxfordshire & Buckinghamshire Cluster intends that, by 2013, the people of Oxfordshire will:

- be healthier, particularly if they are vulnerable or live in our most deprived communities
- be working with us to promote physical and mental wellbeing and prevent ill health
- be actively supported to manage their health and care needs at home when this is appropriate
- have access to high quality, personalised, safe and appropriate health services
- get excellent value from their local health services

Oxfordshire is the most rural county in south east England and has a large geographical area to cover as well as a diverse population to serve. The population of Oxfordshire ranges from a predominantly older, white population in the rural areas to very ethnically diverse populations in Banbury and Oxford city where one third of the population are students.

The NHS in Oxfordshire works with our communities and our partners to improve health in the area and to make sure that local people’s needs are being met. We also work with organisations from the voluntary, private and community sectors so that we can make sure that the organisations providing health and social care services are working effectively.
Area covered by NHS Buckinghamshire & Oxfordshire Cluster in Oxfordshire

The NHS in Oxfordshire serves a population of approximately 675,000 and covers the areas of Cherwell Vale District Council, Oxford City, South Oxfordshire, Vale of White Horse District Council and West Oxfordshire District Council.
2. Executive summary

2.1 Purpose of the public engagement

The Communications and Engagement directorate at NHS Buckinghamshire and Oxfordshire cluster embarked on a period of engagement from 9 May to 25 July 2011, to engage and involve carers that look after individuals with mental health problems in Oxfordshire as well those interested in mental health/Carer support.

Contracts for current services for Mental Health Carers are due to be renewed and so the consultation needed to review what support Mental Health Carers need and find most useful to ensure that services:

- effectively meet their needs
- deliver high quality support
- support prevention, recovery and innovation
- create efficiencies and are cost effective
- deliver services that do not duplicate what already exist

2.2 Process & Methodology

A number of consultation and engagement methods were used simultaneously to enable maximum feedback from a wide variety of stakeholders in the time available. Hard copy surveys were shared at Carers’ groups, mental health support services and relevant events across the county. Online engagement methods on the ‘Talking Health’ website were also used – an online survey and feedback via email or by phone were available to stakeholders. In addition visits were offered to local Carers’ groups to gather face-to-face feedback.

2.3 Key Findings

Analysis of the consultation survey findings resulted in the following themes emerging…

- More and better information on the support services available to Mental Health Carers

A strong theme emerged regarding the limited and fragmented knowledge of support services that are currently available to mental health Carers. Many Carers did not know where to obtain such information and also told us that many health and social care professionals had limited knowledge of what support was out there. Suggestions were put forward for a comprehensive information pack on support services for Mental Health Carers when they are first identified as being a Carer. However it should be noted that online support was ranked the lowest importance for support services and so any future information developed would need to primarily be hard copy.
- The importance and need for crisis support for Mental Health Carers
  Crisis support for Mental Health Carers was highlighted as the most important support service and also a crisis is the situation in which Carers would need support the most. Some Carers also highlighted that crisis support needs to be available 24/7 and those offering crisis support needed to have knowledge of mental health.

- The need and benefits of having specialised support services for Mental Health Carers
  The majority of respondents emphasised the importance of having specialised support services for Mental Health Carers. Many felt they needed support from someone that understood both the variety/complexity of mental health problems and coping strategies for Carers as well as how to navigate the mental health system on behalf of the person they are caring for.

- Improve accessibility to support services for Mental Health Carers
  The issue of access to services came up a number of times. Many of the respondents had problems accessing certain support services due to their location and difficulties arranging travel. A few also had problems accessing support services due to their working hours. When looking at where support services should be located, responses were quite mixed, but the majority of respondents indicated that services should be equally distributed across the county, with suggestions that support services should be at or close to GP surgeries to improve accessibility.

- The critical importance of the Carer’s own physical health and mental well-being and the need to support this
  Apart from crisis support, maintaining the Carer’s own physical health and mental well-being was cited as being the most important support that is needed for Mental Health Carers. Many respondents also told us that support is needed most when they are ill and find it hard or are unable to do their caring role and that a good GP/Carer relationship is essential.

- Strong support for existing services provided by current specialist mental health providers in addition to other Carers Groups
  The majority of feedback from Carers and other stakeholders highlighted the benefits of specialist mental health Carer services provided by Rethink. In addition other specialist mental health Carer support services were mentioned, such as MIND, Restore and The Elms. Other general Carers groups were also highlighted at specific locations around Oxfordshire.

- Positive feedback for specific types of Carer support
  In particular respondents mentioned the positive benefits of 1:1 or face-to-face support – particularly in a crisis and when Carers are struggling emotionally. Many also gave positive feedback on respite breaks and the benefits of attending training courses to give them confidence and knowledge to cope in their Caring role. Whilst telephone support was said to be useful, some indicated that this was not always practical.
2.4 Conclusion

The report recommends that the participants' concerns from this consultation are fully considered and as many of their comments and suggestions regarding support services for Mental Health Carers are incorporated wherever possible into the future commissioning of these services.
3. Background

3.1 What is a Mental Health Carer?
A Carer is someone of any age who provides regular unpaid support to a partner, family or friend who could not manage without this help. A Mental Health Carer may be caring for someone that is only affected by mental health problems, or for someone who has a combination of mental and physical health problems. This review focused specifically on Mental Health Carers.

3.2 What are support services for Mental Health Carers?
The levels of support services available to Carers of those people with mental health problems can vary widely according to need. However they can include things such as:

- Individual support to Carers and via Carer support groups
- Respite breaks
- Practical help obtaining Carer’s assessments and care plans
- Training and education sessions
- Help for Carers to communicate their needs and views to health and social care staff

3.3 The local context
The aim of the programme for ‘Better Mental Health for Oxfordshire’ is to provide settings in which:

- People can stay well
- When people become unwell they will get better, quicker
- Services will deliver effective, timely and appropriate interventions

There are two major shifts set out in the programme for ‘Better Mental Health for Oxfordshire’

- A move to buying services that provide better health outcomes for the people of Oxfordshire
- A move to personalised services that are offering people the opportunity to plan and purchase their own care or support rather than have it provided for them

Therefore this review and consultation examined what support services should look like to deliver these intended outcomes and to best meet the needs of Mental Health Carers.

3.4 What was the purpose of this consultation?
The purpose of the consultation was to:

- Provide an opportunity for stakeholders to tell us about their experiences of support services for Mental Health Carers – what works and what doesn’t
- Provide an opportunity for all stakeholders to tell us what support is most useful and in what situations Carers need this support the most
3.5 Why are we reviewing these services?
The reason this consultation is happening now to review mental health Carer support services in the county is because:

- Currently Rethink (http://bit.ly/Rethink-oxon) is the contracted provider of the Mental Health Carers Support Service in Oxfordshire. This contract comes to end in July 2011.
- NHS Oxfordshire and Oxfordshire County Council (OCC) have recently redesigned and bought new day time services for people with mental health problems under the Keeping People Well (http://bit.ly/KPWell) programme.
- The Carers Oxfordshire (http://bit.ly/Carer-oxon) service provided by OCC in partnership with Age UK Oxfordshire was launched on 1st April for all adult Carers in the county.

This review needs to ensure that the service model delivered in the future is relevant for Carers today. We need to consider the current needs of Mental Health Carers in the context of the services already provided through general Carers Support Services and the new services under the Keeping People Well programme. This will ensure that we prevent duplication and make best use of the available resources to meet the needs of as many Mental Health Carers as possible.

3.6 Consultation Duration
The consultation for 'Support Services for Mental Health Carers' was launched on 9 May 2011 and was initially intended to close on 1 July, 2011.

Part way through the consultation, it was decided to extend the consultation period to 25 July 2011.

The consultation period was extended in order for us to fully consider the potential impact of the new Carers Oxfordshire service and the Oxfordshire Well-being service over a longer timeframe and to help us understand how the services will link with Mental Health Carers Support.

3.7 How will the feedback be used?
The responses to the consultation will help to inform and shape the support services that are bought going forward for Mental Health Carers and the health outcomes identified.
4. Stakeholders

The stakeholders for the consultation on support services for Mental Health Carers are primarily Carers themselves, but also all those individuals, organisations or groups with an interest in support services for Mental Health Carers, other Carers and mental health services generally.

4.1 Key stakeholders identified

The key stakeholders identified for this consultation included:

Mental Health Carers, families and friends
This was the primary target group as the services being reviewed are to support Mental Health Carers and it is therefore important we hear from them and those close to them what support they really need.

Current Service Providers (including the voluntary sector where appropriate)
Current providers of services to support Mental Health Carers were also contacted to disseminate information to the people that use their services and also for staff to feedback if they wished e.g. Rethink, MIND, Restore and general Carers’ support groups.

Other organisations and groups with an interest in support services for Mental Health Carers
E.g. LINKs, Oxfordshire Community and Voluntary Action (OVCA) and Age UK.

Healthcare professionals/clinical staff
In particular we also wanted to hear from any healthcare professionals that have had experience of supporting Carers and their needs.

Those generally interested in Carer support services and/or mental health
There may also be people in Oxfordshire who, whilst not having any direct personal experience, may have a particular interest in Carer support services and/or mental health. It was important that the consultation was therefore communicated in a way that enabled as many people as possible to participate and did not exclude non-Carers.

Local and Parish Councils
Details of the consultation were shared with all local and parish councils in Oxfordshire asking them to share it with their local communities – in particular any Carers in their community – as well as giving any feedback they might have as local councillors.

The Media
Throughout the project media activity was developed when and where appropriate to ensure communication was open and helpful, and that positive messages were provided to support and enable maximum stakeholder involvement.

Other
When communicating this consultation with the key stakeholders listed above, encouragement was also given to share this information with any individual or organisation that may be interested in issues regarding support services for Mental Health Carers in Oxfordshire.
5. Engagement process

A number of different communication and engagement methods were used in order to ensure we reached and received views and feedback from a wide variety of stakeholders.

5.1 Online Engagement

NHS Oxfordshire’s Talking Health website
An online consultation site was established on the ‘Talking Health’ website to enable stakeholders to fill in the survey on support services for Mental Health Carers online or download supporting material to share.

Websites of key organisations
Information about this consultation was published on the NHS Buckinghamshire & Oxfordshire Cluster website, Oxfordshire Community and Voluntary Action (OVCA) website, and Oxfordshire Carers Forum website.

Staff Intranets
NHS Oxfordshire’s intranet was used to communicate the consultation and available response methods to all staff, encouraging further dissemination of information to organisations and interested individuals.

Online Newsletters
The consultation was communicated widely to all internal and external stakeholders using a variety of electronic newsletters eg. using the Talking Health newsletter to reach external stakeholders and the NHS Oxfordshire weekly staff email news bulletin for internal staff.

Twitter and Facebook
A number of announcements and ‘tweets’ were made on the Twitter and Facebook websites for NHS Oxfordshire about this consultation throughout the duration of it to remind people how they could give their views. These messages reach over 1,300 people on our Twitter page and 550 people on our Facebook page.

Email
Personal invitations to participate in the consultation were emailed directly to all stakeholders that have told NHS Oxfordshire that they had an interest in Carers and/or mental health.
5.2 Face-to-face engagement

Visits to organisations
Face-to-face visits were offered to individual organisations and Carers groups to discuss and promote the Support Services for Mental Health Carers consultation. These visits were intended to discuss informally the needs of Carers and their experiences of support services so far.

Events
The consultation was also promoted at any NHS or health events that took place within the consultation period including the Autism Alert Card Launch event and the Health Check events around the county.

5.3 Written engagement

Surveys
Hard copy, printed versions of the online survey were made available and distributed to many stakeholder groups, shared at all face-to-face engagement opportunities and were also sent out as additional copies were requested from various organisations, individuals and groups.

Newsletters
Information on this consultation was also included in OCVA’s ‘Community Concern’ newsletter.

5.4 Other research

‘Hearsay’ and Carers
In addition to the engagement carried out above, we also looked for any existing research on Carers needs in Oxfordshire.

The 2nd Annual Adult Social Care Services Engagement Event, known as ‘Hearsay’ held in May 2011 included some feedback on general Carers needs and so this has been examined as part of this consultation and the results incorporated into the overall analysis of feedback received.
6. Survey

6.1 Number and geographical spread of responses

118 survey responses were received and these were widely distributed across Oxfordshire, but with a large number of responses clustered in and around Oxford city.

In total there were 118 responses - 63 online and 55 hard copy.

(The larger red circles represent a greater number of respondents in that location)

6.2 Gender of respondents

The majority of responses to this consultation were from women (73%) and just under a quarter of responses were from men.
6.3 Age of respondents

Responses to this consultation were received from all age categories, however the majority of responses were received from those aged between 45 and 65+. The individual most popular age category was 65 and over.

6.4 Survey Results

Your Views

**Question 1:** Thinking about support services for Mental Health Carers, should these...

<table>
<thead>
<tr>
<th>Option</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Be provided as part of the general support services for all carers</td>
<td>26% (30)</td>
</tr>
<tr>
<td>Be provided as a specialist service for mental health carers</td>
<td>59% (69)</td>
</tr>
<tr>
<td>Don't know</td>
<td>3% (4)</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>12% (14)</td>
</tr>
</tbody>
</table>

When asked whether support services for Mental Health Carers should be specialist services or part of a wider, general support services for all Carers, the majority (59%) indicated that these services should be specialist mental health Carer services.
Question 2: To what extent do you agree or disagree with the following statements...

Statement 1: It is easy to find information and advice on support services for Mental Health Carers

The majority of respondents disagreed or strongly disagreed (total of 53 responses) with the statement that information and advice on support services for Mental Health Carers is easy to find. However a small number of respondents did agree that information and advice was easy to find.

Statement 2: It is easy to access support services for Mental Health Carers

The majority of respondents also disagreed or strongly disagreed (53) with the statement that it is easy to access support services for Mental Health Carers. However a small number of respondents did agree that it is easy to access support services.
Statement 3: Support services help to maintain the Carer’s good physical and mental health

The majority of respondents either strongly agreed or agreed with the statement that support services help to maintain the Carer’s good physical and mental health. Only 5 people strongly disagreed with this statement.

Statement 4: Support services help Mental Health Carers to continue to do their caring role

The majority of respondents either strongly agreed or agreed with the statement that support services help to maintain the Carer’s good physical and mental health. Only 5 people strongly disagreed with this statement.
Statement 5: Support services help Mental Health Carers maintain their own independence

The majority of respondents either strongly agreed or agreed with the statement that support services help Mental Health Carers maintain their own independence. Only 5 people strongly disagreed with this statement.
When asked to rank the importance of support services for Mental Health Carers, one-to-one crisis support came out top and was ranked very important by nearly 100 respondents.

Support for the Carer’s psychological health and general well-being also came out fairly high and was ranked very important by nearly 80 respondents. This was closely followed by support to maintain the Carer’s physical health.

The other forms of support – education, respite breaks, support of friends/family, telephone support and face-to-face support - all received similar rankings with between 50 and 64 of respondents ranking these support services as very important.

Advocacy received a slightly lower level of importance with just over 30 people ranking it as high importance.

The support service that was ranked least important by respondents was online support.
Question 4: Where should support services for Mental Health Carers be located?

<table>
<thead>
<tr>
<th>Option</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Where the majority of carers live i.e. where need is greatest</td>
<td>31% (37)</td>
</tr>
<tr>
<td>Equally distributed across the county</td>
<td>18% (24)</td>
</tr>
<tr>
<td>Centrally located in Oxford</td>
<td>7% (11)</td>
</tr>
<tr>
<td>Close to other mental health services</td>
<td>21% (25)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>3% (3)</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>20% (24)</td>
</tr>
</tbody>
</table>

We received a mixed response when respondents were asked where support services for Mental Health Carers should be located. The most popular option with nearly a third of responses was that services should be equally distributed across the county.

21% indicated that Carer support services should be located close to other mental health services and 18% said that they should be located where the majority of Carers live i.e. where need is greatest.

A significant number of respondents replied ‘Other’ (20%). The majority of responses in this option focused around two themes. The first was that support services should be located in or close to GP services:

“Support needs to be located close to the GP’s. This would assist as most GP surgeries are located close to their patients. Furthermore it would help GP’s understand and interact with the vulnerable group within our society and their carers.”

“Attached to GP services and Day centres throughout the county.”

“GPs as first contact to be more informed as to what is available, as they are often first "port of call" for a carer.”

The second theme was around accessibility of support services due to a variety of considerations.

“Not enough consideration is given to carers to still have to work full time to provide for their family.”

“It is often difficult for carers to transport those they are caring for and if all help were in the same location transporting would be easier”
**Question 5:** Is there anything else you would like to tell us about support services for Mental Health Carers?

We received a high response to this optional question. The key themes and some of the responses received are shown below:

- **Awareness of services for Mental Health Carers**
  
  “Unless we are told about your services and this is generally the case, it appears that when we ask for support they assume that you already know all about it. The advertising is very poor.”

  “It took me 10 years to find Rethink.”

  “I find it difficult to know what we’re entitled to as Carers and this is usually through my CPN.”

  “I’ve found Carers’ services to be very low profile or invisible.”

  “It’s a shame I had to find them (Rethink) myself as the social workers and other members of the CMHT never told me about them.”

- **Support for Rethink**
  
  “Rethink has been of enormous help to me during the time of my husband’s illness and since he died. Knowing they were there to provide one-to-one support when needed and a grant for nurturing myself was what kept me together a lot of the time.”

  “I have found the Carers’ support service provided by Rethink invaluable.”

  “In the past, Rethink has been excellent for respite breaks and reflexology.”

  “I wouldn’t be coping as well as I do now without the support from Rethink.”

  “I have found that the help and support I have had from Rethink has been invaluable in terms of having someone to talk to who understands the problems and is able to give practical advice and suggestions, and having someone who understands the system and can explain what it is available.”

- **Accessibility Issues**
  
  “Being invited to meetings/groups is impractical in Didcot/Oxford. Our son lives in Henley and doesn't drive.”

  “Oxford is too far for me to travel to Carers’ meetings.”

  “Ensure services are within reasonable travelling time.”

  “A crisis can occur at any time - not necessarily week day times.”
• 1:1 or face-to-face support

"Knowing they were there to provide one-to-one support when needed and a grant for
nurturing myself was what kept me together a lot of the time."

“There is need for one-to-one crisis support at all times of day and night."

“Face to face help is essential. You can’t stay on the telephone when you are caring for
someone with Alzheimer’s”

“Would like more face to face services provided for Carers in obtaining benefits advice”

Other comments included those around the need for support staff to understand mental
health to give Carers’ support; concerns about services and the ability of Carers to cope if
cuts were made; the need for financial support in certain situations and for services to be
available in a crisis.
Your Experience of Support Services

**Question 6:** Please select all that apply…

<table>
<thead>
<tr>
<th>Option</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am a Carer</td>
<td>41%</td>
</tr>
<tr>
<td>I know someone that is a Carer</td>
<td>11%</td>
</tr>
<tr>
<td>I work in a field related to Carer’s support services</td>
<td>5%</td>
</tr>
<tr>
<td>I am interested in Carer’s support services</td>
<td>15%</td>
</tr>
<tr>
<td>I am interested in Mental Health services</td>
<td>20%</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>8%</td>
</tr>
</tbody>
</table>

When we asked the respondents to tell us about themselves, the majority of people said that they are a Carer (41%), or knew someone that is a Carer (11%).

20% of respondents were interested in Mental Health services and 15% were interested in Carer Support services. A small number of respondents (5%) also work in a field related to Carer support services.

**Question 7:** If you are a Carer, are you mainly...

<table>
<thead>
<tr>
<th>Option</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>A Carer of someone with mental health problems</td>
<td>71%</td>
</tr>
<tr>
<td>A Carer of someone with other health conditions</td>
<td>2%</td>
</tr>
<tr>
<td>Both</td>
<td>27%</td>
</tr>
</tbody>
</table>

Of the respondents that were Carers, 71% of these were Carers of someone with mental health problems and a further 27% cared for someone with both mental health and other health conditions.

**Question 8:** Do you or have you in the past used Carer support services?

<table>
<thead>
<tr>
<th>Option</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>75% (88)</td>
</tr>
<tr>
<td>No</td>
<td>16% (19)</td>
</tr>
<tr>
<td>No, but I know someone that does use these services</td>
<td>7% (8)</td>
</tr>
<tr>
<td>Don’t know/can’t remember</td>
<td>3% (3)</td>
</tr>
</tbody>
</table>

Three quarters of respondents had used some sort of Carer support services in the past and a further 7% knew someone else that had used Carer support services. The remainder either had not used support services or could not remember.
**Question 9:** Were the support services that you used specifically for Mental Health Carers?

<table>
<thead>
<tr>
<th>Option</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>84% (76)</td>
</tr>
<tr>
<td>No</td>
<td>12% (11)</td>
</tr>
<tr>
<td>Don't know/can't remember</td>
<td>3% (3)</td>
</tr>
</tbody>
</table>

The majority of respondents that had used Carer support services (84%) said that the services they used were specifically for Mental Health Carers. Only 12% had not used support services specifically for Mental Health Carers.

**Question 10:** If you can remember, please let us know which support services these were:

There were 76 responses to this optional question. Of the responses received, 49 of these were positive feedback related to the services that Rethink offer, with references to their support groups, 1:1 and crisis support.

15 further responses referred to other general Carer support groups including the Oxford Carers Centre and Carer’s centres in Banbury, Didcot, Henley, Witney and other locations around the county.

Other responses included references to support provided by MIND, Oxfordshire Friends and Family Empowerment service (OFAFE), Restore, The Elms, Oxfordshire and Buckinghamshire Mental Health NHS Trust (OBMH)\(^1\), family therapy and respite.

**Question 11:** What services have been most helpful to you?
(Please give examples and, if possible, why they were helpful)

77 responses were received to this optional question. The service that was mentioned frequently as being most helpful to respondents with 42% of the results was Rethink. Comments in support of their service included:

“Rethink helped me to be strong and still care.”

“Rethink provided v helpful respite funding - helpful advice in crises and support with Carers assessments”

“Rethink provides excellent advice, education courses, and much needed respite breaks.”

“Rethink - because they provided brilliant one-to-one support.”

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\(^1\) OBMH is now part of Oxford Health Foundation NHS Trust
A further 16% of responses related to other Carers’ groups in Oxfordshire and the help that they had received through them. The remainder of responses referred to things such as support groups, respite, 1:1 support and training but did not mention specific organisations.

**Question 12: In what situations do you/ would you need support the most?**

102 responses were received to this optional question. The majority (54%) of responses indicated that the type of support that is needed the most is crisis support:

"When there is a crisis, i.e. when the relative becomes physically ill as this very quickly leads to mental deterioration without lots of careful care.”

"More intense contact to help through crisis.”

"When my daughter is in a crisis herself and we all feel unsupported.”

"In times of crisis the support has been crucial in giving me the confidence to ask and fight for help for my son and getting help to get him the right benefits advice.”

14% of responses highlighted that support is needed most when either the Carer or the person that they care for becomes ill.

"When I or my wife are ill or when we are both ill.”

"Becoming ill myself.”

13% of responses related to need respite/breaks from the caring role.

"Given time to talk and time to rest.”

"For long-term situations, to give them breaks.”

12% of responses related to Carers needing clearer information and help to understand mental health and/or how the mental health system works.

"Understanding the the wide majority of needs and moods of patients with mental health problems and the available methods of addressing these needs.”

"Just being able to talk to someone who understands what I’m saying regarding my son’s mental health issue.”

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2 Please note that some respondents gave more than one situation in which support would be needed the most.
12% of responses also indicated that support is needed most when either the Carer of the person they care for has emotional needs.

"When my wife was distressed and becoming unwell the emotional support was extremely important to my wellbeing."

"A situation when the person one is caring for is emotionally unstable and demanding."

Other responses received included that support is needed most in situations where financial help is needed; on a day-to-day/regular basis; support as an early preventative measure to stop situations getting worse; and in situations where Carers have other commitments which conflict eg. work.
7. Engagement Findings – Other methods

7.1 Visits to Carers Groups

Face-to-face visits were offered to individual organisations and Carers groups to discuss their views on the 'Support Services for Mental Health Carers' consultation. These visits were intended to discuss informally the needs of Carers and their experiences of support services so far.

The groups visited are shown below, along with the key themes of the discussion held.

**West Indian Lunch club - 27 May 2011**
This group consisted of approximately 10 Carers.
Their views were:

- A good relationship with your GP is essential
- Need to be assertive if you want to get the support that you need
- Need more information on medication regarding what it's for and why it's needed
- Staff need to listen to Carers as they are most in contact with the patient and understand normal behaviour of patient and therefore can spot if medication does not appear to be working.
- Staff need to understand more about different cultures. In this case, West Indian, and realise that body language and the way West Indian people express themselves (with lots of gestures and hand movements) is not meant to be offensive.

**Mind Carers Group and the Carers Reference group – 9 June 2011**
These groups consisted of approximately 7 Carers at the Mind Carers group and 14 Carers at the Carers Reference group. Their views were:

- More information is needed on mental health conditions/medication/education sessions
- It is useful to be supported by people in a similar position in a group setting
- Having someone knowledgeable in the group to navigate through the mental health system is needed
- Would like to see more access to 1 to 1 support
- A greater understanding of Users and Carers rights under Mental Health Act
- Support is needed most in times of severe need, especially when patients are admitted
- Help is needed for Carers to understand the mental health system, the expectations of care for the service user, involvement and their rights
- More communication is needed with staff in times of severe need/crisis about what will happen to user
- More communication is needed about recovery planning for service users
- Recognition that when the service user is no longer under regular care of the ward or CMHT that although the intensive need may have subsided the Carer remains the main person caring for that person and therefore needs to be 'in the loop' and included in care planning
Rethink Carers Support Group, Abingdon – 16 June 2011
This group consisted of approximately 10 Carers.
These Carers informed us that they had all filled in and returned the survey form. So this particular meeting worked as a group visit to capture any additional views, comments, or information that had not been included in the survey form.

Key themes from the discussions included:

- Support for Rethink as a service aimed specifically at Mental Health Carers

  “My GP didn’t even know I was registered as a Carer. It was Rethink that helped us to register as a carer otherwise I wouldn’t have.”

  “It is through Rethink that we find out practical information such as whether we may be eligible for Carers allowance.”

  “In terms of what works as support for a mental health carer sometimes a phone call is all you need. Rethink are at the end of the phone. They are not judgemental and if you don’t know something a member of staff contacts you promptly. Also she (member of Rethink) phones us when she hasn’t heard from us in a while which is very reassuring.”

- The need for more and clearer information on support services available for Carers

  “Nobody asked us if we were new to the business - we were not given an information pack, no list of who’s who.

  “When my daughter was first diagnosed - I was so confused - you need a little package - something to look at because you are so confused - particularly for first time carers.”

- Improve communication between professionals and Mental Health Carers

  “How social workers and clinical teams communicate with us is patchy and not consistent. They claim that they are there for us as well as our children - but we have to seek out information all the time, it is not volunteered - it is one way communication. Also I can't think of a time when they have rung us up to ask how are you?”

- The need for specific support services for Mental Health Carers

  “We don’t get as good a service as generic carers. Alzheimer’s is recognised, Learning Disability is recognised, and in the Oxfordshire Carers Forum - the most well supported carers are Dementia. This is why voluntary sector support is so vital because they can be more specific for mental health.”
Putting the needs of the person they care for above themselves
It seemed difficult for many of the Abingdon Carers to think in terms of their own support needs separate from the people they cared for. One of the Carers even stated she disliked the term Carer:

"I don't consider myself a carer - I'm a support."

In addition the group were asked what they would do with direct payments for their own support if they had it? The group unanimously agreed that they would use a system of direct payment for their own support needs as an expenses top-up system. For example to use to top up the benefits the person they care for receives; to cover the costs of travel expenses; or to provide back-up income whilst the person they care for works towards re-entering paid employment.

7.2 ‘Hearsay!’ – feedback on Carers Services
The Hearsay! Event was held by the Oxfordshire Local Involvement Network (LINK) in May 2011. The purpose of the event was to find out if the issues raised at last year’s Hearsay! event had been resolved and also to ask guests what they wanted Social and Community Services in Oxfordshire to work on this coming year.

As part of the workshops held during this day, feedback on general Carers support services was included. A summary of this feedback is shown below:

- The need for good quality respite care, but also for help for carers to get out with the person they look after, not just to get away from them
- Concerns there will not be enough money for services for the person they care for
- The need for more crisis support for Carers
- The need for more and better information on the full range of support services available – both for Carers and for health and social care staff that come into contact with Carers
- Support for training courses for Carers to empower them and give them confidence
- More communication needed between health and social care professionals
- Easier access to support services is needed
8. Key Recommendations

The consultation and engagement findings support the following recommendations for Support Services for Mental Health Carers:

- Continue to commission (buy) support services that offer specialist knowledge of Mental Health. This is because Carers have told us that a specialist service is what they need to effectively support them when caring for someone with mental health problems and also enables them navigate the mental health system.

- Ensure investment continues in robust crisis support services as this is when Mental Health Carers need support the most.

- Develop and promote information on the full range of support services that exist for Mental Health Carers to increase awareness as many have told us that they do not know what is available.

- Consider the accessibility of future mental health support services and how these can be made more easily accessible to Carers in their local area.

9. Next steps

A copy of this consultation report will be made available by electronic or hard copy to all those that participated in the consultation regarding support services for Mental Health Carers in Oxfordshire and will also be available for download on our website at: http://www.oxfordshirepct.nhs.uk

The report will use by the NHS Buckinghamshire and Oxfordshire Cluster to help to inform and shape the support services that are bought going forward for Mental Health Carers and the health outcomes identified.

A report will also be made in the future on how the feedback received in this consultation about support services for Mental Health Carers impacts on the final delivery of services and all comments will be recorded on Talking Health at a later date.

10. Thanks

Thanks to all those individuals and organisations that responded to this consultation and in particular to Carers of those affected by mental health problems who shared their personal experiences of support services.
12. Supporting information

Definitions

- Stakeholders - A person or group with a direct interest, involvement, or investment in something. Stakeholders are individuals or organisations that have a direct interest in a service being provided.

Glossary

- CCG - Clinical Commissioning Group
- Facebook - Social networking website
- Intranet - A private computer network open to users working within an organisation to share information, news and documents
- NHS - National Health Service
- OFAFE - Oxfordshire Friends and Family Empowerment service
- OBMH – Oxfordshire and Buckinghamshire Mental Health Trust (now part of Oxford Health NHS Foundation Trust)
- PCT - Primary Care Trust
- Twitter - Twitter is a social networking tool aimed at enabling its users to exchange up-to-the-minute news and opinions on specific topics.
- Talking Health - NHS Oxfordshire’s consultation and engagement area on our public website (see https://consult.oxfordshirepct.nhs.uk)
13. Appendices

Appendix 1: Survey

SURVEY
A review of Support Services for Mental Health Carers in Oxfordshire

We recommend reading the background information before answering this survey. The survey will take approximately 5 minutes to complete. Thank you for your participation.

Your Views

1. Thinking about support services for Mental Health Carers, should these...

☐ Be provided as part of the general support services for all Carers
☐ Be provided as a specialist service for Mental Health Carers
☐ Don't know
☐ Other (please specify)

2. To what extent do you agree or disagree with the following statements?

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither agree or disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>It is easy to find information and advice on support services for Mental Health Carers</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>It is easy to access support services for Mental Health Carers</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Support services help to maintain the Carer's good physical and mental health</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Support services help Mental Health Carers to continue to do their caring role</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Support services help Mental Health Carers maintain their own independence</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
</tbody>
</table>
3. Please rank the importance of each of the following support services for Mental Health Carers with a value from 0 to 5.

- 0 = Don’t know
- 1 = Not Important
- 2 = Low importance
- 3 = Neutral
- 4 = Important
- 5 = Very important

<table>
<thead>
<tr>
<th>Support Service</th>
<th>Please rank each row from 0 to 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>One-to-one crisis support</td>
<td></td>
</tr>
<tr>
<td>Face-to-face support e.g. individually or in groups</td>
<td></td>
</tr>
<tr>
<td>Telephone support and advice</td>
<td></td>
</tr>
<tr>
<td>Online support and advice</td>
<td></td>
</tr>
<tr>
<td>Support to maintain the Carer’s psychological health and general well-being</td>
<td></td>
</tr>
<tr>
<td>Support to maintain the Carer’s physical health</td>
<td></td>
</tr>
<tr>
<td>Practical support e.g. applying for benefits, help to get a Carer’s assessment</td>
<td></td>
</tr>
<tr>
<td>Support of friends/family and other social networks</td>
<td></td>
</tr>
<tr>
<td>Respite breaks</td>
<td></td>
</tr>
<tr>
<td>Advocacy</td>
<td></td>
</tr>
<tr>
<td>Education and training for Carers</td>
<td></td>
</tr>
</tbody>
</table>

4. Where should support services for Mental Health Carers be located?

- Where the majority of carers live i.e. where need is greatest
- Equally distributed across the county
- Centrally located in Oxford
- Close to other mental health services
- Don't know
- Other (please specify)
5. Is there anything else you would like to tell us about support services for Mental Health Carers?


Your Experience of Support Services
6. Please select all that apply

☐ I am a Carer
☐ I know someone that is a Carer
☐ I work in a field related to Carer’s support services
☐ I am interested in Carer’s support services
☐ I am interested in Mental Health services
☐ Other (please specify)

7. If you are a Carer, are you mainly...

☐ A Carer of someone with mental health problems
☐ A Carer of someone with other health conditions
☐ Both
☐ Not applicable

8. Do you or have you in the past used Carer support services?

☐ Yes
☐ No (jump to question 12)
☐ No, but I know someone that does use these services (jump to question 12)
☐ Don't know/can't remember (jump to question 12)

9. Were the support services that you used specifically for Mental Health Carers?

☐ Yes
☐ No
☐ Don't know

10. If you can remember, please let us know which support services these were:
11. What services have been most helpful to you?  
(Please give examples and, if possible, why they were helpful)

12. In what situations do you/ would you need support the most?

About You
Your age
- ☐ Under 16
- ☐ 16-24
- ☐ 25-34
- ☐ 35-44
- ☐ 45-54
- ☐ 55-64
- ☐ 65 and over
- ☐ Prefer not to say

Gender
- ☐ Male
- ☐ Female
- ☐ Prefer not to say

Ethnicity/Race
- ☐ White
- ☐ Mixed
- ☐ Asian or Asian British
- ☐ Black or Black British
- ☐ Chinese
- ☐ Prefer not to say
- ☐ Other (please specify)

Postcode
This will be used to assess where we are receiving responses from across Oxfordshire

Please provide your name and address or email below if you would like to receive a copy of the consultation report.