



HEALTHWATCH KENT: MENTAL HEALTH CARERS

**What is the experience of mental health carers in
Kent?**

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What is Healthwatch Kent?

Healthwatch Kent was established in April 2013 as the new independent consumer champion created to gather and represent the views of our community. Healthwatch plays a role at both national and local level and makes sure that the views of the public and people who use services are taken into account.

What do we do?

Healthwatch Kent took over the role of Kent Local Involvement Network (LINK) and also represents the views of people who use services, carers and the public to the people who commission plan and provide services. Healthwatch provides a FREE signposting service for people who are unsure where to go for help. Healthwatch can also report concerns about the quality of health care to Healthwatch England, and the Care Quality Commission to take action.

Our Mission Statement

Our mission is to raise the public's voice to improve the quality of local health and social care services in Kent. We listen to you about your experiences of health and social care services and take your voice to the people who commission health and social care services in Kent.

Our FREE Information and Signposting service can help you navigate Kent's complicated health and social care system to ensure you can find and access the services that are available for you. Call us on 0808 801 0102 or email info@healthwatchkent.co.uk

Our Values

- Volunteer led (5 staff, 60 volunteers)
- Information and Intelligence based
- Support and Guidance
- Two way communications
- Partnerships and relationships - achieve more in partnership than alone
- Honest, accountable and transparent

Background

Healthwatch Kent has heard concerns from members of the public, voluntary organisations and health professionals from all over Kent about the experience of Carers for mental health patients and the support available to them.

Linked to this, we have recently completed a project which looked at general issues facing mental health services in Kent and the experience of patients and carers involved. The findings from this horizon scanning confirmed that we needed to undertake a more detailed study into the experience and needs of carers of people living with a serious mental health illness.

Activmob were commissioned to undertake a detailed study on our behalf. They spoke with a number of patients and professionals to capture their experience. In September we invited a number of mental health carers,

mental health commissioners, relevant voluntary organisations, and providers of mental health services together. At that meeting we discussed the insights that we had gathered and discussed ways in which we could collectively move forward and make improvements for mental health carers.

This report summarises the feedback we received from carers and the discussions from the September event.

Our Objectives

The objectives of the project were:

- - To engage and speak with mental health carers from across Kent and get an in-depth understanding of the experience and reality they are facing.
 - To capture the specific needs, aspirations and experiences of those caring for people with a serious mental illness
 - To increase understanding amongst stakeholders including those that provide and commission mental health services about what it is really like to care for someone with a serious mental illness
 - To facilitate better working relationships between carers and health professionals
 - To collectively agree on a way forward for everyone

Our Approach

We identified a number of individuals and organisations who could help us to reach mental health carers, particularly those people who may not traditionally speak out.

We spoke initially with local carer groups (4 groups) and the Mental Health Action Groups either face to face or by telephone using our prepared Topic Guide (appendix 2). We attended the East Kent Carers Council and Maidstone Carers Group. We spoke to representatives of Rethink Groups in Sittingbourne and West Kent.

Using these trusted carer groups and forums enabled us to speak to many other carers across Kent. Depending on what method the carer preferred we spoke to people either face to face, over the phone or by email using the Topic Guide. We spoke to an additional 17 people.

We also ran a workshop to review the initial findings. 12 people attended including carers, representatives from the Mental Health Action Group, Kent & Medway Social Partnership Trust (KMPT) and carers organisations.

The experiences that people shared with us were used as the basis for discussion at a meeting on September 10th. A number of people were invited to that discussion including Kent County Council, KMPT, mental health commissioners from the Clinical Commissioning Groups, voluntary organisations and mental health carers.

The discussions from the September meeting have been combined with the experiences people shared with us to formulate this report and our recommendations.

What People Told Us

Individuals and organisations shared with us the following issues and concerns.

Life of a carer

- The impact of caring for a person with a Serious Mental Illness is immeasurable in most cases and a lack of understanding and support can increase stress, anxiety and ill-health.
- Mental Health carers feel stigmatised and marginalised by the professionals that provide services and feel there is an expectation that they carry the burden of caring without support to allow them to do so.
- Carers feel that there is no understanding of what their life is really like and no will to try to understand.
- Not enough transparency around issues of confidentiality, what can be shared and under what circumstances? The Carers Guide to Confidentiality document is difficult to find and often there seems to be a very local interpretation of its content.
- The cost of transport is prohibitive in a lot of cases and emphasis is put on carers to transport those they care for from hospital to dentist appointments etc. at great cost both in time and money.

Frustrations of Mental Health Carers

- A perceived lack of transparency around bed closures has left many carers frustrated and angry, feeling that this issue is not being addressed fully and that questions are not being answered.
- Carers told us that they feel that engagement is on the whole a tokenistic activity as nothing seems to change. Carers feel that the only way they can get the needs of those they care for met is to *'play the system'*.
- Not enough notice is given for meetings. Also, meetings held in the middle of the day add to the sense that engagement is not

meaningful as there is no recognition that they may have life and work away from those they care for.

Involvement in care

- Carers told us they feel left out of the discharge planning and are often left with no information regarding transition of care. Some carers told us that on occasion they had been given no information about plans to discharge the patient
- Not enough emphasis is put on advanced care planning to ensure the wishes of the patient are recorded for when they become unwell.
- Carers should have the appropriate level of involvement in the ongoing planning, care and treatment of those they care for in the community. Carers report that there is confusion over where to go or who to contact when there is a crisis, and what can feel like a 'revolving door' through a variety of mental health acute wards both in and out of Kent does not help recovery.

Support for Carers

- An understanding that the carer has the right to an assessment of their own needs and information about the emotional, practical and financial support available is patchy and inconsistent. Often the best source of good information is through the experience of other carers.
- Access to support groups and/or carers forums is, in some cases, difficult to navigate due to inconsistent signposting from professionals. However carers who are accessing groups such as East Kent Carers Council and Maidstone Carers (amongst others) find them an invaluable source of support, friendship and understanding.
- Carers told us that since the re-commissioning of carers services, their needs are not always being fully met. In some areas, support is often phone based and not robust enough to cope with the complex

issues being presented. (We do understand that some organisations offer more tailored support to carers, including face to face support, however the carers we spoke to felt their needs were not always met).

- Support in the community is lacking, carers report that they may be given a named contact in case of a crisis but the person is never available when needed. GPs tell carers to call the crisis team in an emergency, and often carers feel this is a pointless exercise as nothing is done.
- Carers have to learn to navigate systems almost in spite of the professionals ***“you have to find your own way through to what you need, people don’t know what’s available locally”***.

Culture

- Carers report that the culture in Mental Health services is very old fashioned and ‘traditional’ and a more enlightened approach to engaging with carers is needed to ensure that everyone involved in the care of their loved one is engaged and informed, with better use of the **‘open dialogue approach’** which aims to engage patients and their families and networks in dialogue.
- Carers feel that the balance between the needs of the service users and their carers is not always right and that the ‘old assumptions’ are still very much in play.

Other Challenges

- High turnover of staff, poor continuity of care, lack of available resources and getting their voice heard were some of the other challenges identified by carers. Carer support networks are generally good at providing emotional support but there is no capacity to deal with practical things.

- Carers have a genuine fear for the future. They worry about what will happen to those they care for when they are no longer able to care themselves or when they become the cared for.

DISCUSSION AREAS

A number of ideas emerged through the study. These ideas were as follows:

- The establishment of a **Mental Health Carers Forum** that looks to meaningfully engage with carers of all ages across the county of Kent.
- The **design and co-production** of an effective working relationship between commissioners/funders such as NHS England, Kent County Council and the Clinical Commissioning Groups, providers such as KMPT and the voluntary sector. This needs to explore issues such as the Triangle of Care, Advanced Care Planning and the development of a carers charter.
- Design a **programme of awareness raising and training** for staff which provides insight into what caring for someone with a Serious Mental Illness is really like; which seeks to improve relationships and remove barriers and overcomes challenges to working together.

These three ideas formed the basis of a discussion at the September workshop. From those discussions the following key themes emerged.

Carers concerns - General

Carers told us that they felt their concerns often went unacknowledged by professionals. A key outcome for the carers attending was for commissioners and providers to listen to their stories and take appropriate action.

The group were played recordings of two carers describing their experiences as mental health carers and their feelings of frustration and concern. Carers who attended the workshop felt dejected at hearing the stories of their fellow carers and stressed that it was unacceptable for people to have such experiences.

KMPT also highlighted that many of the issues raised at the Workshop reflected the responses to their own carers survey recently undertaken. An action plan has been drawn up by KMPT to address these issues.

Action: Provide practical training for carers to help them in their role as carers. The brief for the training should involve carers in determining the key objectives and outcomes. Training could potentially be provided by KMPT. Many Carer organisations already provide some training for carers so this should be looked at and built on to avoid duplication.

Confidentiality:

It was felt that carers needed further reassurances that their needs would be met and they would be looked after. Of equal importance, however, was the desire for 'reality and honesty' on the part of the service providers when handling carers' concerns. Some were worried that the quality of communication - '*how you are dealt with*' - can often come down to the personality of the individual representing the local authority. Confidentiality - though sacrosanct in medical practice - can actually be an obstacle to some carers, who feel unable to effectively respond and care without the co-operation of some GPs and support workers.

The fear of 'stonewalling' - of authorities not responding or reacting to anxious carers - was a point repeatedly raised by carers. Some felt that practitioners and providers would play the '*confidentiality card*' to avoid confrontation. Whilst this suspicion clearly frustrates mental health carers, it was also noted that mental health support staff often seemed overstretched and under-resourced.

Action: It was agreed that clearer guidance and protocols on confidentiality would be developed by KMPT in collaboration with carers, commissioners and other providers involved in the care of people living with serious mental health issues. The guidance would help clarify for carers what can and cannot be shared.

Staffing and training:

Carers were keen to highlight the need for continuity and expertise among staff dealing with mental health needs. There was a worry that the number ongoing changes in personnel could be very damaging for the patients, and it was put to Healthwatch Kent to investigate why there may be such a high level of change.

For those carers who attended the workshop who normally do not go to meetings with commissioners and providers, their fears primarily involved gaps in training for frontline staff. They were keen to advocate training in how to build a trusting relationship with people suffering from mental health problems - and take steps towards managing staff turnover and maintaining those relationships.

KMPT highlighted that they had begun to implement protocols as to when practitioners and support workers should engage with carers.

Action: KMPT advised the Workshop that they were already working with carers to train their staff and they would seek to extend this approach. It was also agreed that the focus should be on *how* staff engage with carers as well as *when*.

Communication:

A breakdown in communication was a recurrent theme for the duration of the workshop and KMPT agreed to improve their communication with all carers. Although KMPT have many groups for carers, it was clear that many

carers are not receiving updates about the work that KMPT are doing to support carers.

Action: A monthly newsletter by KMPT for carers was suggested. Work would need to be done to ensure the distribution list covered as many carers as possible.

Action: KMPT to draft a breakdown of services and make it clearer what patients and carers can expect from each service

Mental Health Carers - Platform:

KMPT highlighted that they have a *'range of engagement and consultation groups'*, including a programme that would see carers involved in the training of service providers. This was very much welcomed by the group. It was suggested that the Mental Health Action Groups (MHAG) could also support this.

Action: To put in place a suitable platform to hear carers' voices, inform the commissioning strategy and put the Carers' Charter into action.

NEXT STEPS & ACTIONS

Develop a clear **Action Plan building on the ideas highlighted in this report from the Workshop:** to be developed by a small "Task and Finish" Group led by Healthwatch Kent. Membership of this Group to include: MHAGs, carers, commissioners and service providers.

The Workshop also identified and agreed the following immediate actions

- KMPT to develop clear policy and protocol on confidentiality for carers, patients and practitioners;

- West Kent Clinical Commissioning Group to request performance data on support offered to mental health carers from now on;
- Link the feedback from these discussions with KMPT's own Carers Survey;
- KMPT to work together with Carers to agree a Carers' Charter;
- KMPT to develop suitable training for carers in their role as carers;
- KMPT to improve communication and involvement of carers in on-going and future initiatives led by KMPT;
- Commissioners and other service providers to improve communication with carers;
- KMPT to communicate guidelines on what all services should be delivering;
- Healthwatch Kent will organise a session with the Kent Health and Wellbeing Board on carers. The aim of the session will be to develop and agree a set of principles for carers across Kent. This is already scheduled for the January Kent Health & Well Being Board.

Further actions and initiatives such as a County wide forum for mental health carers will be discussed and developed as part of a detailed action plan.

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 - East Kent Carers' Council
 - Rethink
 - Mental Health Action Groups
 - East Kent Carers' Consortium

 - The participants in our Discussion workshop
 - All the carers involved
 - Kent County Council
 - West Kent Clinical Commissioning Group
 - East Kent mental health commissioner
 - Kent & Medway Social Partnership Trust
 - Mental Health Action Groupⁱ
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