



Carers' Strategy 2008-2011

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Oxleas NHS Foundation Trust

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Foreword

Improving the carer experience

Improving the support provided to families and carers is one of our four 'must do' objectives. This is in recognition of the invaluable role that many families and carers play in supporting someone throughout illness and on the journey to recovery. Being a carer can have a profound impact upon a person's life, and many carers value support from services to enable them to continue to care and to maintain their own health and wellbeing.

This year, the Government has launched the National Carers' Strategy *Carers at the heart of 21st - century families and communities* (2008) which clearly emphasises the importance of the NHS in supporting carers. Our services have a key role to play in identifying carers, providing them with timely information and advice and helping them to access support for themselves. One of the trust's values is viewing things through the eyes of the people who use our services and their carers.

We have focused this strategy on the areas that carers have told us matter to them, and are working towards a vision where all carers feel recognised for their invaluable role and, wherever possible, are involved as true partners in care.

We have a profound admiration and respect for everyone undertaking a caring role for a person with a mental illness or learning disability, and we hope this strategy meets our carers' expectations. We look forward to continuing to work with both carers and partner organisations to improve the carer experience.

David Mellish - Chair

Stephen Firn - Chief Executive





Introduction

Support from family members, friends or neighbours is often critically important for someone with ill health or a disability. Carers offer a range of emotional and practical forms of support and, without this, many people would not be able to live independent or fulfilling lives.

5.2 million people in the UK provide unpaid help and support to individuals who are ill, frail or disabled (Census 2001) and this number is likely to increase as the population expands and ages. A recent report estimated that carers save the country £87 billion a year; this amounts to £15,000 per carer per year (Carers UK, 2007).

Caring for someone can be a rewarding experience but it can also be very challenging. Caring can impact upon family life, friendships and social relations, health and wellbeing, finances, and the ability to work or pursue education or leisure activities. Some carers are faced with additional challenges, for example carers from black and minority ethnic (BME) communities report difficulties associated with a lack of cultural understanding from some professionals, language barriers, and resistance within their own community. Young carers can face difficulties juggling their responsibilities at school and home, and social exclusion from their peers.

Mental health and learning disability caring

Carers of people with a mental illness or learning disability may have to deal with difficult or unusual behaviour, changes in personality and family dynamics, and sometimes verbal and/or physical aggression. Carers may feel isolated by the stigma still attached to mental illness, and the lack of understanding and support from others. Caring for someone with mental ill health or a learning disability may have the additional stress of being an unpredictable and/or lifelong commitment.

It is estimated that 40-50% of all carers care for people with a mental illness or a learning disability (Keeley and Clarke, 2002), many of whom will be under the care of secondary services. Oxleas may be the only service in direct contact with carers, and, as such, we have a crucial role in both identifying and supporting carers.





Who is a carer?

Oxleas defines a carer as:

A person who provides, or intends to provide, unpaid practical or emotional care and support to someone with an illness or disability. They may be a relative, partner, neighbour or friend. A carer may be of any age and may be a young person providing support to a parent or another person. A carer may live with the person they care for or they may provide support from a distance.

This is a broad definition and reflects the individual and changeable nature of caring roles. A broad definition is particularly important in mental health caring where the support provided may not always be 'visible' and may vary over time and even on a day to day basis.

What do carers do?

- Carers provide practical, physical, emotional and sometimes financial support to vulnerable people
- Carers may supervise someone to keep them safe
- Carers may monitor the person and ensure they adhere to treatment
- Carers may help identify signs of relapse, and provide support that helps prevent an admission to hospital
- Carers may help someone deal with the difficult emotions and other problems caused by the illness
- Carers may help someone to access services and get the support they need
- Carers provide the support they do without payment and sometimes without recognition or thanks.

Strategy Development

Why an Oxleas strategy?

Each of the boroughs has a multi-agency strategy to guide the planning, commissioning and delivery of services to carers of all client groups in their borough (Bromley 2007-2010, Greenwich 2007-2010, Bexley under review). This carers' strategy for Oxleas builds on these strategies and details the specific actions planned for improving the support to carers of people under our care.

This strategy is aimed at carers in all our services; adult mental health, older adult mental health, child and adolescent mental health, adult learning disabilities and forensic services. It outlines our priorities for improving our support to families and carers over the next three years.

This strategy complements the Oxleas Family Therapy Strategy which details specific plans around improving access to family interventions.

Carer views

This strategy draws on feedback obtained from carers over several years. Carers' events, carers' forums, and carers' support groups in each of the boroughs have been an arena for carers to express their views and tell us how our services should be improved. Analysis of local surveys and PALS/complaints data has also identified key areas for development. A trust wide carers' event in January 2008 highlighted the ongoing concerns of carers and prompted the development of this strategy.





A specific consultation with carers during March and April 2008 via questionnaire asked people about their experiences, and what they would like to see in a strategy.

The results from the consultation and previous feedback have driven the aims and the actions of this strategy.

Aims

The trust's overall aim is to develop ways of working that ensure that families and carers feel informed and involved in the care of the service user wherever possible. Carers should be recognised and valued for the difficult job that they do, and feel supported to continue in their role if they are happy to do so.

We aim to:

1. Improve our identification of carers
2. Improve our involvement of families and carers
3. Improve our information for families and carers
4. Improve our assessment of carers' needs and development of carers' care plans
5. Improve our support to families and carers at times of crisis
6. Develop the skills and confidence of our workforce in working with families and carers.

1. Improve our identification of carers

Many carers do not recognise their important role. They recognise themselves only as mother, brother, partner, friend etc and do not realise that the support they provide also means they are a carer. BME communities in particular report difficulties identifying with the concept of 'carer' due to pre-existing cultural expectations around care giving, and some languages not having a word which translates into 'carer' (NBCCWN, 2008).

Identifying a carer is the first step in ensuring they are offered an assessment of their own needs and provided with information, advice and support.

We aim to improve our identification of carers.

What we have done:

- Agreed a definition of a carer
- Promoted the identification of carers within care teams and developed guidance for healthcare professionals on registering carers on our records system
- Trebled the number of people formally registered as carers

What we will do:

- Continue to raise awareness of carers and the definition of a carer amongst healthcare teams
- Ensure service users are informed of the trust's commitment to carers, and are asked about the people who support them
- Ensure that our staff actively seek to identify young carers and signpost them to young carers services
- Develop a system of monitoring carers' identification, allowing us to highlight areas for improvement.





2. Improve our involvement of families and carers

What carers have told us they value most is to be actively involved in the care and treatment of the person they care for: to have their opinion listened to, to have their views taken into account when making decisions about the person they care for, and to be kept informed about the illness and treatment.

Both carers and clinicians report confidentiality as a potential barrier to carers feeling involved.

“We need to be involved in the day to day arrangements for dealing with the illness. I appreciate the need for confidentiality but if you have close contact with patient, ie they live with you, you need to know about medication and side effects etc.”

“What has been good is the occasions when the psychiatrist and the CPN work together with the patient and carer as a team.”

We aim to improve our involvement of families and carers in planning the care and treatment of service users.

What we have done:

- Appointed a Trust Carer Lead to take forward the carers' agenda, and ensure a central point for advice and information for healthcare professionals
- Developed and disseminated a carers' charter telling carers what they can expect from our services and how they can be involved

- Developed best practice guidance around sharing information with families/carers to ensure staff are confident in dealing with confidentiality
- Developed an information leaflet about confidentiality, to let service users and carers know their rights
- Piloted email correspondence between community teams and carers.

What we will do:

- Ensure the continuation of the Trust Carer Lead post and consider the development of further carer support posts
- Seek to ensure that through appointment letters, and other correspondence with service users, carers are invited to initial appointments and ward rounds
- Ensure that all teams have clear processes for involving carers in planning care, and that this is reflected in the overall care programme approach (CPA) policy
- Ensure clear processes are in place for the involvement of young carers, including suitable contact/visiting arrangements in inpatient settings
- Ensure that person specifications for healthcare profession jobs include knowledge of carers as an essential requirement
- Seek to include carers on interview panels to ensure new staff are carer aware
- Monitor feedback from complaints and Patient Advice and Liaison Service (PALS) about the carer experience and ensure we identify areas for involving carers more fully.





3. Improve our information for families and carers

Carers tell us that access to information, especially in the early stages, is vital in helping them to understand the illness and to cope with the situation. Carers tell us they would like: specific information about the person they care for, general information about mental illness and treatments, and information about how to cope with and support someone with mental illness.

“Information, especially at the start of the illness, is vital, and honest answers to questions would have helped.”

“I found that instead of being given information, it was a case of asking questions first and then sometimes being given answers. Even still some of the answers were conflicting.”

We aim to improve the information we provide to families and carers.

What we have done:

- Developed an information handbook and a series of leaflets for carers
- Developed carers' information packs for the main inpatient settings
- Begun to install computer sites in inpatient settings for carers to access information available online
- Redesigned the intranet to include accurate and up to date information for health care professionals to give to carers

- Established a medication helpline that carers can ring for information and advice about medications
- Piloted an information prescriptions project that increased our information resources for carers in a range of formats
- Developed a successful carers' art therapy initiative in partnership with Tate Britain
- Held a range of events, conferences and seminars for service users and carers
- Established carers' support groups in all boroughs to ensure carers have access to information
- In some areas developed education/information sessions for carers.

What we will do:

- Continue to develop information resources for carers in a range of formats and languages as need is identified
- Collate current resources and develop further information for young carers
- Ensure all teams have information about their services available for service users and carers
- Ensure teams are informed about the information resources available for carers and how to access them
- Build on existing links with local partners to improve communication exchange. This will ensure new carer initiatives and information are advertised effectively and reach a wide audience
- Redesign the trust website with a range of information accessible to carers
- Continue to run regular events to ensure that carers have access to information
- Develop further training and education initiatives for families and carers to help them in their role.





4. Improve our assessment of carers needs and the development of carer's care plans

Carers who provide substantial and regular care have a right to an assessment of their own needs (Carers (Equal Opportunities) Act 2004) and a carer's care plan (NSF Standard 6, 1999). Carer's assessments and care plans are important tools to help carers identify their own needs, and connect them with support for themselves.

"I found my carer's assessment very helpful, the CPN was understanding to the difficulties I was having and it was good to get it all off my chest."

We aim to improve our rates of carer assessments and carer care plans and ensure all carers are informed of their rights to an assessment.

What we have done:

- Developed a leaflet for carers explaining carer's assessments
- Provided staff training on carer's assessments to increase the knowledge and skills of our workforce
- Employed a carer support worker in one area of the trust to both undertake and assist clinicians to undertake carer's assessments.

What we will do:

- Develop and agree a carers' involvement and assessment policy including procedures for offering, undertaking and reviewing carer's assessments
- Establish clear procedures for assessing the needs of young carers and work with local partners in developing young carer support plans
- Ensure healthcare professionals understand the availability of support for carers and how this is accessed
- Ensure accurate monitoring of carer's assessments, allowing identification of areas for improvement and unmet need
- Work with local partners to develop and coordinate support services for carers to facilitate positive outcomes from carer's assessments
- Work with local partners and carers to increase access to respite and carers' ability to take breaks.





5. Improve our support to families and carers at times of crisis

Families and carers are often the first to notice signs of illness or a relapse. Carers have told us they would like to be listened to when they have concerns, and for professionals to be understanding and responsive. Carers have told us they want clear information about what to do and who to contact in a crisis, and would value having discussed a crisis plan in advance.

“It is very important to know what to do and to have a reliable contact when an intolerable situation has arisen, either when the person you care for is very unwell or when you the carer find you are unable to cope.”

“We need emotional support from the team in times of crisis. We have been given a number to ring if a crisis occurs but it would be better to have a plan in place in advance so we know what to do.”

Carers frequently report concerns about what would happen to the person they care for if something were to happen to them as carer, particularly where the cared for person cannot be left for long periods. Many carers would like to have their own emergency plan in place so that they are reassured the person will be looked after if they were suddenly unable to care.

We aim to increase our crisis planning with carers, our responsiveness at times of crisis, and the information available to carers about crises.

What we have done:

- Distributed crisis information to carers via a carers handbook.

What we will do:

- Develop information resources for carers around coping in a crisis
- Seek to ensure that, wherever possible, carers are involved in developing crisis plans for the person they care for and are given a copy of the care plan
- Develop workshops/courses for carers around crisis planning, relapse, and de-escalation techniques to increase carer knowledge and confidence
- Ensure that planning for a carer's own emergency is considered as part of the carer's assessment.





6. Develop the skills and confidence of our workforce in working with families and carers

Carers have highlighted the important role of our staff. Their understanding and responsiveness, particularly during the carer's first contact with services, is vitally important to carers. Carers tell us they would like professionals to recognise the important role of the carer and seek to work with them in the care of the service user.

"I would like to see improved staff training on dealing with families and carers. Some staff seem to regard families as an unwelcome irritation'."

We aim to develop the skills and confidence of our workforce so that they can be proactive in working with families and carers.

What we have done:

- Developed a range of training packages for health care professionals including three day family inclusive practice training
- Made carers training mandatory for all clinical staff
- Incorporated the carer's perspective into induction training for new staff.

What we will do:

- Develop a workforce training action plan seeking to increase availability of training for healthcare professionals
- Work with colleges/universities to ensure that student healthcare professionals working in the trust have received training in carers issues
- Where possible involve carers in the development and delivery of our training to ensure the carer's perspective is included
- Develop carers awareness e-learning training for non clinical staff
- Ensure that carers issues are included in the supervision of staff and in the personal development review (PDR) process.

Monitoring progress

We want to ensure that carers are central to our work and we will monitor our progress on the strategy with them.

As part of the strategy implementation, a trust wide Carers Strategy Group will be formed to monitor progress. A Carers Development/Steering Group in each borough will oversee local action plans and will feed into both the trust Carers Strategy Group and also local Carers Partnership Groups to ensure a coordinated approach to carer support in each borough. We will seek to have carer representation at each of these groups.

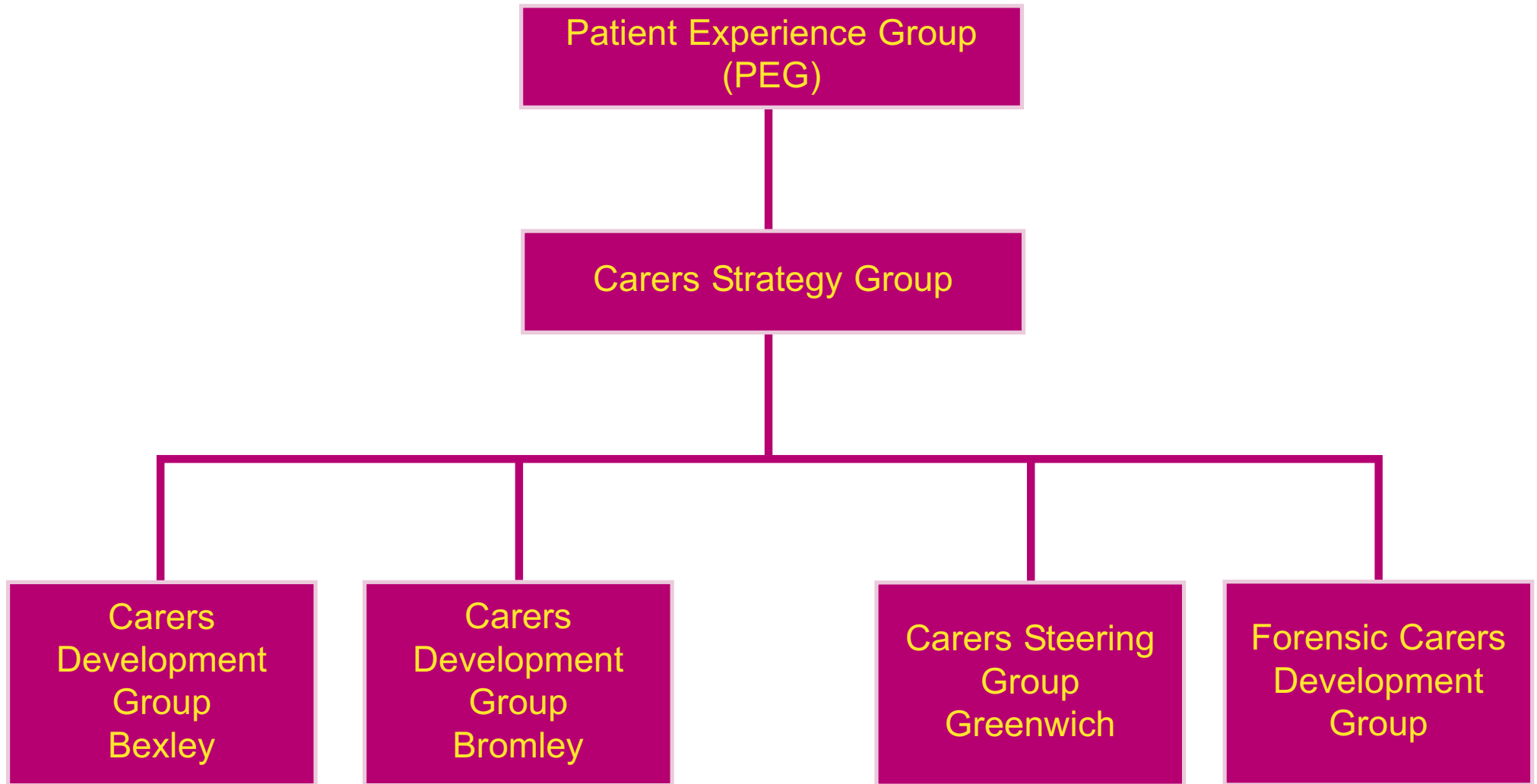
The Carers Strategy Group will report directly to the Patient Experience Group for the trust on a four monthly basis.

The implementation plan will be subject to continual review by the Carers Strategy Group to ensure targets are met.





Monitoring structure within Oxleas





References:

Valuing carers - Calculating the value of unpaid care
Carers UK (2007)

Carers at the heart of 21st - century families and communities: a caring system on your side, a life of your own

Department of Health (2008)

National Service Framework for Mental Health, Standard 6, Caring about carers

Department of Health (1999)

Carers speak out project. Report on findings and recommendations

Keeley B & Clarke M (2002)

Beyond we care: Putting black carers in the picture
National Black Carers and Care Workers Network (NBCCWN) (2008)

Resources for carers

There is a range of leaflets for carers which are available at each trust site. Staff can also print a range of information leaflets and factsheets from the intranet to give to carers.

