

# PAPER

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# Report to the Meeting of the

# Oxford Health NHS Foundation Trust

# Board of Directors

**26 June 2013**

**Draft Carers Strategy**

**For Approval**

The Trust’s Carers Strategy has been developed to reflect the breadth and range of services that the Trust now delivers to patients, service users and carers across five counties. It also includes the most recent legislation, practice and methods of measuring the outcomes which carers want and need and services strive to deliver.

There has been extensive consultation both internally and externally including

Carer and Patient Foundation Trust Members

The Trust’s Board of Governors

Carers Buckinghamshire

Oxfordshire Carers Forum

Age UK

HOSC support officers in Oxfordshire and Buckinghamshire

**Recommendations**

The Trust Board is asked to approve the Trust’s Carers Strategy.

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**CARERS STRATEGY**

**OXFORD HEALTH FOUNDATION TRUST 2012 / 2017**

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1. **Introduction**

This Carers Strategy describes how Oxford Health NHS FT will deliver improvement in recognising, valuing and supporting carers across both its clinical operational Divisions and its geographical areas.

This strategy refers to Carers in their many family and friendship roles as children (Young Carers), parents, daughters, sons, partners and spouses, neighbours and friends. In all of these roles as Carers in their relationships to the care given people provide significant and substantial care.

The Carers Strategy takes account of the organisational growth and development of Oxford Health NHS FT from previously being an organisation solely focussed on the specialist mental health needs of service users and carers, to an organisation which now provides and manages community health and social care services to the wider population in of Oxfordshire as well as mental health services in Buckinghamshire, Swindon, Wiltshire and BaNES. This strategy also takes into account some areas of specialised practice, for example the needs of carers of those with eating disorders and higher functioning autism.

This new Strategy will therefore address the breadth and range of the wider constituency of Carers coming from Specialised Services, Adult and Older Adult Mental Health Services, Children and Family Services and the Community Services.

This Carers Strategy seeks to build partnerships with key third sector organisations in delivering and improving service delivery to Carers.

1. **Definition of the Carers role**

The Princess Royal Trust for Carers offers the following definition of carers and the caring role:

‘A carer is someone of any age who provides unpaid support to family or friends who could not manage without this help. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems.

Anyone can become a carer. Carers come from all walks of life, all cultures and can be of any age. Many feel they are doing what anyone else would in the same situation; looking after their mother, son, or best friend and just getting on with it. Carers don’t choose to become carers: it just happens and they have to get on with it; if they did not do it, who would and what would happen to the person they care for.’ 6

1. **The contribution carers make to services and the personal impact of the caring role**

There is a wide range of documented evidence of both the vital role carers play within their families and social networks and the importance of the financial value of the contribution they make to the care economy.

There is well documented evidence that carers are providing a wide range of interventions to their care recipients, for example: activities of daily living, managing and dealing with incontinence, emotional support, transport, and advocacy. Without the vital contribution Carers make to the care economy, public services nationally and locally would considerably over burdened, underfunded and unable to meet demand.

The impact of caring on carers themselves is also very clearly recognised both in research and local consultation. 1,2 For example there is a particularly high impact on carers of people suffering dementia. The high levels of personal responsibility care givers take mean they report high levels of stress and poorer levels of attention to their own health needs with high levels of physical and mental ill health needs of their own and evidence indicate that caregivers are twice as likely to suffer depressive symptoms as non caregivers. 3, 4

1. **The Needs of Carers**

The documented and long stated needs of Carers themselves continue to describe a well-recognised combination of requirements to support them in their caring role.

These are clearly outlined and summarised in the National Policy – *Recognised Valued and Supported: Next steps for the Carers Strategy.* These needs and issues were also evident from a recent local consultation on carers’ experience led by Oxfordshire County Council.

1. **Needs Identified Nationally**

* Carers need timely access to information – on the illness or condition of the person they are caring for; on appropriate caring; on access to benefits and on financial and employment issues.
* Carers feel excluded by clinicians and often feel that both health and social care professionals are hiding behind rules of confidentiality. Striking a balance in working within rules of confidentiality should respect, inform and involve carers more as expert partners in care.
* Carers find accessing assessments overly bureaucratic and slow, and are often disappointed about the paucity of resources.
* Carers often feel forced to give up work to care.
* Carers often neglect their own health and need advice to maintain their well-being.
* Carers need breaks from caring to sustain their caring role.
* Carers feel the value of the Carers Allowance is inadequate, the overlapping rules around benefits and the earnings limit is a disincentive to work.
* More should be done to identify and support Young Carers. 5

1. **Needs and Issues Identified Locally**

Carers of people with mental health problems are more likely to identify significant barriers to early identification of mental and physical ill health.

Those carers caring for children with mental health conditions report that there are barriers to accessing appropriate respite services as well as being able to access appropriate advice and information to support them in their caring role. They also report issues around ensuring successful transition to adult services.

Young carers experience a range of significant negative impacts of caring, on health, wellbeing and educational attainment. Local stakeholders report that due to low young carer awareness among relevant professionals such ‘symptoms’ of caring can be taken at face value and acted upon, rather than identifying the young person as a carer. Alternatively, young carers are often not identified and/or supported by services.

There are large numbers of ‘hidden carers’, particularly people who are early in their caring role and/or have lower intensity caring roles. This has implications for the prevention agenda and may signal a lack of carer awareness in key areas of service. 2

1. **Carers of people with learning disabilities and parents/carers with a learning disability**

Oxford Health NHS FT recognises the significant contribution that carers of people with learning disabilities and carers with learning disabilities make to the quality of the experience that people with learning disabilities have when accessing our services. A key aim of the Trust is to improve the experience of carers of people with learning disabilities in order to improve quality of life for service users with learning disabilities. The Trust endeavours to support families in their caring role and wishes to ensure that carers of people with learning disabilities and carers with a learning disability know about their right to an assessment of their needs and that services are appropriately provided to carers in response to such assessments.

Oxford Health NHS FT will undertake work to understand the experience of carers of people with learning disabilities and the experience of carers with learning disabilities to find most useful ways of increasing their accessibility of this information.

1. **Strategic Outcome Measures**

The strategic outcome measures this strategy will adopt come from national and local consultation with Carers in their caring roles. These measures will form the basis of a carer outcome framework against which Oxford Health NHS FT will report its performance and progress.

Carer Outcomes:

The outcomes below have been selected from both national and local consultations with Carers in their caring roles and are therefore based on their experience and their views of the focus for improvement.

* Carers are respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role.
* Carers are able to have a life of their own alongside their caring role.
* Carers are supported so that they are not forced into financial hardship by their caring role.
* Carers are supported to stay mentally and physically well and treated with dignity.
* Children and Young people are protected from inappropriate caring and have the support they need to learn, develop, thrive and enjoy positive childhoods.
* Carers are identified at an early stage, informed about care services and assessed in a timely way to identify their own needs for services.
* Carers are informed and advised about the illness condition of the person they support in a caring role with. 5

The outcomes above will form the basis of a consistent framework of carer outcomes which will be measured, recorded and reported by Oxford Health through three key methods.

* Community and inpatient teams being delegated responsibility to routinely seek feedback from individual carer’s about their experiences and outcomes.
* Establishing and facilitating representative focus groups of carers receiving direct services and with current experience of inpatient and community services, informing the organisation and key partners about their experiences and outcomes.
* Performance activity information obtained through the Trust’s electronic clinical record system eg the number of carers assessments completed; reporting the numbers of carers accessing the Local AuthorityCarers Grant to fund respite care and other services to support them in their caring role.

Each Division will identify champions and performance leads who will coordinate and report performance information plus facilitate the direct feedback about experiences of Carers.

In measuring outcomes in this way progress will be described through the narrative of carers themselves and through performance activity.

1. **Establishing Leadership and Divisional Action Plans to drive improvement forward**

The Chief Operating Officer is the Executive Lead for Carers in the Trust. Clinical Divisional Senior Management Teams will be responsible for delivering the strategy within the services they manage through the development and delivery of activities appropriate for the patients and carers they serve to deliver the outcomes set out above. A proposed reporting structure is set out below.

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| --- | --- | --- | --- |
| **Report to whom** | **Lead Officer** | **Where** | **Frequency** |
| Trust Board | Chief Operating Officer | Trust Board | Year ending report March 2014 onwards |
| Local Authority organisations, Care Commissioning Groups and Carers representatives | Heads of Social Care and Divisional Performance Leads | Provider and Commissioning Joint Management Groups for Oxfordshire and Buckinghamshire | Bi-annual from July 2013 onwards |
| Executive Team | Divisional SMTs | Divisional Performance Meetings | Quarterly from September 2013 |

**References**

1. Shah / Wadoo / Latoo. BMJP 2010; 3(3): a327 - Psychological Distress – Carers of People with Mental Disorder
2. Oxfordshire evidence report draft summary.
3. Amkhanyou, A.A., Wolf D.A. – Caregiver stress and Non-caregiver stress: Exploring pathways of psychiatric morbidity. Genealogist. 2003
4. Danhauer, S.C., McCann J.J., Gilley,D.W., Beckett, L.A., Bienias, J.L., Evans D.A. – Do behavioural disturbances in persons with Alzheimer’s disease predict caregiver depression overtime? Psychology and Aging 2004
5. Recognised, Valued and Supported: Next steps for the Carers Strategy
6. What is a Carer? – Princess Royal Trust for Carers.
7. <http://www.carers.org/what-carer>