Foreword
In addition to young carers and young adult carers (see separate response), Carers Trust has selected these three groups:
- Carers of people with mental health problems
- Carers of people with dementia
- Older carers
as a priority based on what we hear from carers in these groups about the particular issues they face, what Carers Trust Network Partners tell us (see main response for detail about Network Partners), and the increasing demographic issue of carers of people with dementia and older carers.

Carers of People with Mental Health Problems

Introduction
There are approximately 1.5 million carers of people with mental health problems in the UK. When considering how best services can help them it is important to consider their experiences of services. Whilst the Care Act 2014 for carers focusses primarily on local authority responsibility the majority of carers of people with mental health problems are in the most part or solely in contact with the NHS or health services. It is this contact with health services that can mean that unless their NHS trust is cooperating with their local authority closely, many carers of people with mental health problems remain within health services and may not be receiving the support for their wellbeing they need.

Specific Issues affecting Carers of People with Mental Health Problems

Confidentiality
Carers of people with mental health problems experience specific challenges that mean that they often go unidentified and unsupported for longer. The trauma of mental illness can cause tension in families which may mean that the person with mental health problems states they don’t want their family involved. Or, due to their illness have delusions that involve their family. The challenges of mental illness can therefore mean that:
- Carers are excluded at certain points of the care pathway
- They are not listened to or informed of important information they require to help them support the person they care for.
- They are not informed of support for themselves.
- Professionals miss out on vital information that can inform treatment and care.
- Carer exclusion can lead to key information being missed by professionals that can have a detrimental impact on the care of the person with mental health problems.
health problems and in worst case scenarios: serious and untoward incidents\(^1\).

These issues are often exacerbated by poor staff training (at both pre-registration and during induction) of health care staff (of all types) in confidentiality and information sharing. Even though the Caldicott Principles\(^2\) were revised in 2013 to include an additional principle on the value of sharing information and the Mental Health Act 1983 – Code of Practice\(^3\) was revised in 2015 which gave clearer guidance on listening to and including carers (of all ages); carers continue experience exclusion from key points in the mental health carer pathway.

**Lack of Carer Awareness & Understanding of Carer Need**

Despite recent legislation and a range of guidance from NHS England and third party organisations, mental health services continue to provide inconsistent information, advice and support to carers of people with mental health problems. Carers Trust’s Triangle of Care programme in England has gone some way to start to identify underlying issues and address them with mental health services, however, the culture of mental health services still places carers in a “silo” away from the main business of mental health provision.

A number of mental health trusts have identified key areas that have begun to address the issues as a result of the Triangle of Care programme, these include:

- Making carers and the Triangle of Care an organisational priority, this goes beyond a CQUIN which is often too short term to address the underlying cultural issues.
- Ensure the organisation has a strategic carer lead as well as an operational carer lead who is able to drive through long term cultural change, it’s important that this goes beyond mere “participation”.
- Embed clear and robust support for the Triangle of Care and carers through a network of supported and training “carer champions”.
- Build strong links and work in partnership with local carer organisations who are able to act as expert partners to the improvement of carer identification and support in secondary services.

**Complexity of Mental Health & Stigma**

Serious mental illness is a complex and stigmatised condition that not only the person experiencing it but also those providing care. As a result of stigma, many carers are not identified, do not feel they can approach or join “general” carer groups

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1 Report of family not listened to in Matthew Daley case May 2016: [http://www.huffingtonpost.co.uk/entry/father-of-road-rage-murder-accused-matthew-daley-condemns-sons-mental-health-treatment_uk_57333bc5e4b06da49a73adf](http://www.huffingtonpost.co.uk/entry/father-of-road-rage-murder-accused-matthew-daley-condemns-sons-mental-health-treatment_uk_57333bc5e4b06da49a73adf)

2 Information: To Share or Not to Share, The Government’s Response to the Caldicott Review, September 2013, Crown

and services and in some cases experience stigma from professionals who see them as partially the cause of the mental illness of the person they care for.\(^4\)

**Location of Treatment & Support**

It is important to note when considering the experiences of carers of people with mental health problems with whom and where they experience services. Legislation pertaining to carers (specifically Care Act 2014 and Children and Families Act 2014) tend to refer to identification and support of carers in relation to local authorities with the NHS discussed in terms of collaboration as opposed to a requirement to identify and support. As most people with mental health problems (and by default those who provide care and support for them) tend to only experience services within a mental health trust (especially if this service is an integrated trust) then many carers never come into contact with their local authority. As such carers often go unidentified and unsupported for many years, reasons for this include:

- Health services work on a medical model as opposed to a holistic model
- Health professionals of all type do not receive mandatory carer awareness training
- There is still confusion with health professionals around confidentiality and information sharing, with many staff airing on the side of caution due to punitive confidentiality agreements.
- There is not a requirement to identify and support carers within the NHS mandate.

**Lack of understanding of Mental Health & Carers in Primary Care**

Carers Trust’s Network Partners have highlighted primary care as a key area of challenge and anxiety for carers of people with mental health problems. With a number of people being discharged from secondary mental health services to the care of their GP; carers have found that the vital link they had to expertise and knowledge is lost. Many also cite the issue of GPs poor understanding of the value of carer inclusion and carer identification as an ongoing issue; with this being exacerbated by poor understanding of mental health by primary care services.

**Recommendation for Improving the Experiences of Carers of People with Mental Health Problems**

It is important to recognise that the issues identified above are key issues for carers of people with mental health problems and that these issues affect adult and young carers alike. For more specific examples of experiences refer to the Triangle of Care 2\(^{nd}\) edition and the Triangle of Care for Young and Young Adult Carers.\(^5\) Therefore

\(^4\) Walter, G. The Attitude of Health Professionals Towards Carers and Individuals with Mental Illness, 2009, Australian Psychiatry

\(^5\) Hannan. R & Mitchell. A, The Triangle of Care for Young Carers and Young Adult Carers, Carers Trust, 2015
recommendations should be considered for carers of all ages taking into account specific challenges faced by young carers.

Recommendations:

- It is a requirement (in legislation) for NHS services (and those commissioned that sit outside of the NHS) to identify carers (of all ages) at first contact or as soon as possible thereafter.
- Carer awareness and a whole family model of care is developed as part of mandatory pre-registration training for all health professionals.
- The Triangle of Care model of carer involvement and support is a requirement for all mental health services, with clear funding, support and guidance provided to ensure clear long term cultural change is achieved.
- Improved confidentiality and information sharing training is developed for health professionals to address issues that lead to carer exclusion from key points in the care pathway.
- Better commissioned carer support services which enable providers to provide the skilled support required to carers of people with mental health problems.
- Clearer working between health and social care so that carers of people with mental health problems are not disadvantaged.

Carers of People with Dementia

Key Issues for Carers of People with Dementia

Carers Trust’s research into the experiences and needs of carers of people with dementia, demonstrates clearly what the issues faced by this group of carers experience. A Road Less Rocky, sets ten key crisis points when carers of people with dementia need specific, information, advice and support in their own right to prepare for and cope with their caring journey. These are:

- When dementia is diagnosed,
- When the carer takes on an “active” caring role,
- When the capacity of the person with dementia declines,
- When the carer needs emotional support and/or a break from caring,
- When the person with dementia loses their mobility,
- When the person with dementia has other health problems,
- When the carer has to cope with behavioural problems,
- When the carer’s own circumstances change,
- When the person with dementia becomes incontinent,
- When decisions about residential care and end of life care have to be made


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Carers are still going unidentified at an early enough point whereby they reach crisis point at one of these later points which has long term implications for their own health and wellbeing and often leads to the person they care for being admitted to residential care.

Acute Hospital Experience
Carers of people with dementia experience particular challenges in relation to acute hospital admissions where they are excluded from the admission and discharge procedure; as a result their expertise is lost by the hospital staff (usually treating the person with dementia for a different issue)\(^7\). It can also lead to unsafe discharge and significant issues for carers and people with dementia alike\(^8\).

Recommendations
Carers of people with dementia experience particular challenges that are in addition to the wider issues experienced by all carers. Often due to their age, the nature and complexity of dementia and their own health needs they are a particularly vulnerable group who need attention in their own right. It is important to note many current dementia initiatives do not fully take into account the unique needs of carers of people with dementia, placing their focus on those with the condition and assuming that this will address carers’ needs at the same time.

With these in mind Carers Trust would recommend that:

- Acute hospitals develop their carer awareness to ensure that carers are included throughout the care pathway which would reduce reduce poor discharge practices.
- Commissioners (including CCGs) ensure carers of people with dementia are included in commissioning decisions including ensuring their own needs (as identified in the Road Less Rocky) are taken into account when commissioning services.

Older Carers

The 2011 Census revealed that there are over 1.8 million carers aged 60 and over in England including: 151,674 who are aged between 80 and 84 and 87,346 who are over 85.

The numbers of older carers is growing all the time, those aged 85 and over grew by 128% in the last decade (Carers UK and Age UK, 2015).

\(^7\) Hannan, R, Thompson, R et al, The Triangle of Care, Carers Included: A Guide to Best Practice for Dementia Care, Carers Trust, 2013.

\(^8\) Parliamentary and Health Service Ombudsman, A report of Investigations into Unsafe Discharge from Hospital, 2016
Older carers have their own specific needs and have tended to be a forgotten group, often going unidentified because they do not recognise themselves as a carer or are not recognised by services. With an aging population and the increase in the life expectancy of people with learning disabilities which is to be celebrated; people are caring for longer and later in their lives.

Key issues for older carers include, it is also worth referring to a number of reports produced by Carers Trust which support this:

- Lack of recognition of their own health needs and the impact of caring on their own health and wellbeing.
- Isolation and loneliness, especially in relation to unavailable, inappropriate or inaccessible transport.
- Complex management and navigation models of health and social care systems with no support.
- Lack of preparation including a lack of awareness of the likelihood for caring in later life, especially so for carers who have been caring for children with long term conditions whose life expectancy meant they were unlikely to reach old age but increasing numbers now are.
- Older carers have a strong sense of “duty to care”, this can be reinforced by health and social care professionals which means they may feel they have no choice or continue to do so longer than they are able.
- Lack of information on financial planning, including information on lasting powers of attorney are not provided at an early enough point.

Recommendations:
In light of the issues experienced by older carers, Carers Trust makes the following recommendations:

- Primary and secondary health services must implement a requirement to identify older carers as early as possible and ensure they are referred for support in their own right.
- Planning for caring in later life should be considered as a public health priority and the public supported to plan for their own care needs and the potential for becoming a carer in later life.
- Health and social care systems must be aligned and integrated to ensure older carers are not required to navigate the complex systems for both their own and the person they care for’s health needs.
- There must be improved information and guidance on financial planning including information on Lasting Powers of Attorney to ensure carers are prepared for the future and are not required to address these issues too late in their caring journey.

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9 Marks. L, Retirement on Hold, Carers Trust, 2016 (due to be published January 2017)
10 Fraser. M, Always on Call, Always Concerned, Carers Trust, 2011
11 Caring about Older Carers: Providing Support for People Caring in Later Life, Carers Trust, 2015
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- Public, community and hospital transport must be improved to address issues of isolation and loneliness which are particularly acute issues for older carers.
- Clearer support and guidance to help carers navigate a complex health and care system.

Specific Issue for EU and (non-EU) Migrants
A number of Carers Trust Network Partners have highlighted issues for EU migrants accessing support as carers, as well as mental health support in their own right. Now that the results of the EU referendum have been finalised it is important to recognise the impact of the change to the UK’s EU status on carers who were not born in the UK.

Case Study
Mrs W has lived in the UK for approximately 7 years. She is married to a British citizen and worked for the British Medical Association when she first arrived here from Italy (where she had previously lived with her husband). Mr W has a diagnosis of schizophrenia and she left work to care for him. More recently she, herself, developed mental health problems and was referred to secondary mental health community services. She received poor treatment and was referred to as ‘health tourist’. She is now under the Complex Depression and Anxiety Service. Also at an earlier appointment with a psychiatrist she was informed she may be suffering with a personality disorder. Unfortunately the mental health assessment she received did not feel she was eligible for this service.

Mrs W has struggled to receive benefits in her own right, but is included on her husband’s claim. The relationship between them is now rather strained. Mrs W is receiving support from a Carers Trust Network Partner but her own ill-health is impacting on their progress.