THE TRIANGLE OF CARE

Carers Included:
A Guide to Best Practice for Dementia Care
ACKNOWLEDGEMENTS

The creation of the Triangle of Care has taken many years and involved many people. It celebrates a developing awareness of carers’ needs and demonstrates that in different parts of the UK those people who work with and on behalf of carers are creating excellent resources and better outcomes.

The original impetus to identify ways of ‘improving engagement between professionals and carers’ grew from a training programme created by carers in Devon. Similar initiatives grew in other places. The work of Lu Duhig in Avon and Wiltshire influenced this resource in many ways.

Funded through the RCN Foundation, the development of a Triangle of Care for dementia in 2016 was a collaborative effort between the Royal College of Nursing and Carers Trust. It was co-designed with carers, people living with dementia and practitioners, with the support of Uniting Carers and Dementia UK.

The Triangle of Care for Dementia was developed in recognition of the need to improve carer involvement in hospital settings, but its application is relevant across all settings.

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The Triangle of Care describes a therapeutic alliance between service user, staff member and carer that promotes safety, supports recovery and sustains wellbeing.

Although the Triangle of Care was originally developed for use in mental health services, the standards outlined below have been found applicable in other care settings. This guide demonstrates how these standards can be used to support a partnership approach to dementia care, particularly in hospital settings.

The Triangle of Care for Dementia describes how meaningful involvement and inclusion of carers can lead to better care for people living with dementia. In an ideal situation the needs of the carer and the person living with dementia are both met. Inclusion of people living with dementia and support in making decisions is therefore fundamental to its success. This will then complete the triangle.

The Royal College of Nursing project Dignity in Dementia; Transforming General Hospital Care (2011) highlighted that involving family carers was highly instrumental in supporting improvements in care and was seen as a high priority by people living with dementia, carers and practitioners. Including and supporting carers of people living with dementia will lead to better outcomes for patients, carers and ultimately the professionals supporting them (Royal College of Nursing, 2013).

Carers and staff have so much to learn from each other – they need to work together to get the best for the person who has dementia.

Person living with dementia

The staff have to make me feel that I am part of the care and that my husband is definitely part of it, because particularly for people with dementia, it has to be a joint venture.

Unpaid carer

The key elements to achieving a Triangle of Care

The essence of this guide is to clearly identify the six key elements (standards) required to achieve better collaboration and partnership with carers in the service user and carer’s journey through mental health services.

For each element we suggest good practice examples and resources that may be helpful.

1 Although the terminology and legislation referred to in this guide applies to England the standards and rationale are applicable across the whole of the UK.
The six key standards state that:

1) Carers and the essential role they play are identified at first contact or as soon as possible thereafter.

2) Staff are ‘carer aware’ and trained in carer engagement strategies.

3) Policy and practice protocols re: confidentiality and sharing information, are in place.

4) Defined post(s) responsible for carers are in place.

5) A carer introduction to the service and staff is available, with a relevant range of information across the care pathway.

6) A range of carer support services is available.

In addition to the above, there also needs to be regular assessing and auditing to ensure these six key standards of carer engagement exist and remain in place. A self-assessment audit tool for carer engagement can be found in the Triangle of Care website.

Who is this document for?

This guide is primarily addressed to those involved in the care of people living with dementia in hospital settings, although the principles are applicable across other settings. It applies to health, social care and third sector services, directors, managers, commissioners and staff. It can also be used to inform carers, people living with dementia and carer groups. Success in achieving change depends upon staff becoming willing ‘champions’ for better partnership working and being able to challenge practice that excludes carers.

A more inclusive attitude for carers and families should be promoted, where they are listened to, heard and consulted more closely. Balancing the needs of both the person living with dementia and their carer is vital in achieving the best outcomes.

Better recognition that carers are key partners in the planning and provision of care also makes sound economic sense.
THE TRIANGLE OF CARE: A CARER ENGAGEMENT APPROACH FOR SERVICES SUPPORTING PEOPLE LIVING WITH DEMENTIA.

The Triangle of Care was developed in mental health services and Carers Trust works with mental health providers and other health and care settings to implement the Triangle of Care in their services.

The Triangle of Care approach is aimed at encouraging partnership working with carers at all levels of care from the individual to overall service planning.

The Triangle of Care for Dementia has built on the original guide and applies the same standards to services caring for people living with dementia. While this guide has a focus on dementia services, the principles can be applied within other settings such as care homes and community services.

Including carers in care and treatment will:

- Offer better outcomes for the person living with dementia.
- Enable staff and services to ensure they have a fuller picture of the person’s needs and how their dementia affects their behavior and general wellbeing.
- Provide peace of mind for carers that the person they care for is receiving the best and appropriate treatment possible.

This guide focuses on carers as they are often excluded from care particularly within inpatient services.

Carers can help in a number of ways including:

- Providing valuable information and history.
- Communicating with the person living with dementia.
- Offering support and reassurance to the person living with dementia.

Carers and relatives should have the opportunity to be involved in decisions about care and treatment. Dementia is a degenerative condition which can affect a person’s insight, capacity and ability to make decisions. This can result in differing views and needs between people living with dementia and those caring for them. While the person living with dementia has capacity they must be supported to make their own decisions and articulate

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views. However, if they lack capacity, health and social care professionals must act in the ‘best interests’ of the person living with dementia, bearing in mind the provisions of the Mental Capacity Act (2005). Balancing the needs and views of carers with those of the person living with dementia is essential within this.

The Triangle of Care for Dementia builds on the NICE guidance principles of person-centred care underpinning good practice in dementia care, which highlight both person-centredness and relationships.

- The human value of people living with dementia (regardless of age or cognitive impairment) and their families and carers.
- The individuality of people living with dementia, and how their personality and life experiences influence their response to dementia.
- The importance of the person’s perspective.
- The importance of relationships and interactions with others to the person living with dementia, and their potential for promoting wellbeing.

A disconnected model of involvement like this can lead to carers being excluded at important points.

This leads to gaps in practice which can result in the carer being left on the outside and in failure to share information that may be vital to assessment, care planning, and to acting in the best interests of both the person living with dementia and the carer.

“My husband’s doctor spoke to him about his medication when I wasn’t there. When I asked what had been said I was told there was no need as my husband had been told already. Unfortunately, my husband had no memory of the details of the conversation.”
Unpaid carer

Carers say their wish to be effective is commonly thwarted by failures in communication.

At critical points they can be excluded by staff, and requests for helpful information, support and advice are not heard.

The Triangle of Care can be part of the solution.

The concept of a triangle has been proposed by many carers who wish to be thought of as active partners within the care team. This requires collaboration between the professional, person living with dementia and carer.
An effective Triangle of Care will only be complete if there is a willingness by the professional and carer to engage. Most carers recognise that this three-way partnership between the person living with dementia, carer and professional, with all the voices being heard and influencing care, will produce the best outcomes. As dementia is a progressive condition, which can affect a person’s ability to make decisions for themself and/or communicate their wishes, carers may need at times to act on their behalf. However, every effort should be made to ensure that the person living with dementia is included in decision making. This requires an understanding of dementia and skill in how to support communication for people living with dementia.

“We should never assume that by talking to the carer that you don’t need to talk to the person with dementia, both need to be included.”

Unpaid carer

Although many carers want to be involved, services may have traditional ways of doing things which create obstacles for carer inclusion. More effective carer engagement will grow from changing attitudes and adopting positive practice. This relationship can be reinforced by putting in place key components which invite carer participation and give information, support and advice in a considered manner. This should involve carers in all stages of the process including assessment, treatment, referrals and discharge planning, as well as decisions in such areas as care provision and housing. It is also essential that carers are involved in decisions about and provision of end of life care.

There should be consideration of the wider circle around the person and thought should be given to those offering support who may be seldom seen, for instance young and young adult carers.

“The TOC (Triangle of Care) is a living everyday reminder that we must never forget our people are inextricably interconnected with their family, partner or friend unit.”

Executive Director of Nursing and Carer Experience, Mental Health Foundation Trust

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Unpaid carer

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Executive Director of Nursing and Carer Experience, Mental Health Foundation Trust
WHY IS CARER ENGAGEMENT SO IMPORTANT IN DEMENTIA CARE?

Carers have a crucial role to play in the care of people living with dementia. When a person living with dementia develops a physical health problem and/or their behaviour changes the carer is often the first to be aware of this. If that person is admitted to hospital or a care home it is often the carer who knows the person’s history and is able to provide care staff with crucial information. Carers can also help support communication and share information with the person living with dementia. This helps to ensure that the right care and treatment is provided which takes into account additional support needs and preferences.

Carers want a collaborative team approach to care, and to be seen as partners in care.

Carers want to be kept involved and informed throughout assessment, treatment and discharge planning for the person they care for.

“Willingness to involve carers and utilise their knowledge can increase the ability to get things right first time, saving resources and time and using everyone’s expertise for the good of all.”
Unpaid carer

Carers of people living with dementia also have their own needs, which need to be assessed and taken into account. It is essential that carers have good support to enable them to manage the stresses and demands of caregiving.

Carers often face higher levels of loneliness and isolation as a person living with dementia care needs grow. And carers have increased health needs themselves and can suffer detriment to their physical health.

It is carers who are responsible for care when the professionals aren’t there, and as the condition progresses are commonly faced with coordinating and managing complex needs.

“When looking at the needs of the person with dementia it is absolutely essential to link this strongly with the needs of the carer(s). The two are inexorably joined.”
Person living with dementia
Admission to hospital can be very distressing for people living with dementia but it is also a time when carer engagement needs to be given special attention.

Carer involvement is fundamental to good care delivery and carers need to be kept informed at all stages of care including discharge planning. Carers also need to feel included in the delivery of care and supported with their own needs. This is particularly important if the person is at the end of life.

Practice Examples

NICE 2020 Clinical Knowledge Summaries - How should a carer’s needs be assessed?, Scenario: Management | Management | Support for adult carers | CKS | NICE

Alzheimer's Society 2023 Caring for a person with dementia: A practical guide | Alzheimer’s Society (alzheimers.org.uk)

Dementia UK 2020 Dementia Strategy 2020-2025 Dementia-UK-2020-2025-strategy.pdf (dementiauk.org)

Practice Examples

Marie Curie 2022 Caring for someone with dementia towards the end of life Dementia towards the end of life | Information for professionals (mariecurie.org.uk)

British Geriatrics Society 2022 BGS Position Statement: Person-centred acute hospital care for people with dementia | British Geriatrics Society says:

“Family and other carers of people with dementia require special attention and inclusion, to enable gathering of medical and other information, to inform about problems and progress, to assist in decision-making and discharge planning, and to help with ‘hands-on’ occupation, feeding assistance and personal care, where they are able and willing”.

John's Campaign (2022) John’s Campaign -for the right to stay with people with dementia, for the right of people with dementia to be supported by their family carers, Available at: John's Campaign (johnscampaign.org.uk)
CREATING THE TRIANGLE OF CARE

In the Triangle of Care you will find ways of achieving better collaboration between the clinician/team/ward, person living with dementia and carer, based on the six key standards which make up an effective triangle.

The rationale for each of these standards is explained, and examples of best practice highlighted. Planning to achieve an effective Triangle of Care is based on the recognition that the service needs to ensure each element is put in place to create and sustain the engagement required to achieve better outcomes.

The Triangle of Care approach can be used to improve carer-staff interactions wherever they take place on the care pathway. Carers are usually willing to work with staff and do what they can to help improve the health and care needs of the person they care for.

They often value the professionals temporarily taking over the responsibility from them and giving them space to reflect. They then may gain more understanding of how to manage their caring role and how to get support in doing so. However, they may also need help and reassurance in relinquishing their role and being confident in the care being given.

“It is enormously stressful for a carer to pass their loved one into the care of someone who doesn’t know them. We need family carers to have the chance to work with the hospital team, not feel they’re fighting against them. If the carer is stressed, that’s not going to support the patient, and it’s not going to enhance the chances of a return home.” Unpaid carer
THE KEY ELEMENTS TO ACHIEVING A TRIANGLE OF CARE

The essence of this approach is to clearly identify the six key standards required to achieve better collaboration and partnership between staff, carer(s) and the person living with dementia. For each standard you will find best practice examples and resources that may be helpful.

1) Carers and the essential role they play are identified at first contact or as soon as possible thereafter.
   - Carers are identified and have their needs assessed along with the person living with dementia.
   - Carers’ views and knowledge are sought, shared, used and regularly updated as overall care plans and strategies to support treatment and care are developed.

2) Staff are ‘carer aware’ and trained in carer engagement strategies.
   - Staff need to be aware of and welcome the valuable contribution carers can make and be mindful of carers’ own needs as well as the needs of people living with dementia.
   - Staff need knowledge, training and support to become carer aware.

3) Policy and practice protocols re: confidentiality and sharing information, are in place.
   To ensure proactive engagement, carers need to be part of the care planning and treatment process across the care pathway, that is, for inpatient, home treatment and community, the service should have clear policies and mechanisms and ensure these are routinely used, including:
   - Guidelines on confidentiality and for sharing information – a three-way process between the person living with dementia, carers and professionals – which includes assessment of capacity and best interest decisions.
   - Protocols and approaches that facilitate information sharing.
   - Use of lasting power of attorney, advance directives or plans.
4) Defined post(s) responsible for carers are in place, including:

- Carers lead or champion (these may have different names within your organisation) for all wards and teams who are skilled and knowledgeable about dementia.

5) A carer introduction to the service and staff is available, with a relevant range of information across the care pathway, including:

- An introductory letter from the team or ward explaining the nature of the service provided and who to contact.

- An appointment with a named member of the team to discuss their views and involvement.

- Ward or team orientation/induction procedure and leaflet.

- Carer information packs.

- Discharge planning and aftercare support.

6) A range of carer support services is available, including:

- Carer support through a carer support or condition specific organisation

- Carers needs assessment, referral to a statutory assessment

- Mechanisms for gathering feedback which are used to inform service improvement.

There also needs to be regular (at least annual) assessing and auditing to ensure the six key standards of carer engagement exist and remain in place.

To support you to evidence how you meet the standards, a self-assessment guide and toolkit are available.
THE RATIONALE BEHIND THE KEY ELEMENTS

1) **Carers and the essential role they play are identified at first contact or as soon as possible thereafter.**

Staff need to identify who are the carer(s), - for example the person or people who are providing significant support - their relationship with the person living with dementia and the level of support they provide. The carer’s views and knowledge then needs to be recorded and shared with the team. Carers often possess crucial information as a result of their close relationship and contact with the person living with dementia. Their early involvement will help provide the most accurate assessment on which to plan treatment and care. The carer needs to be part of giving and receiving information and be helped to develop coping strategies vital for successful care. Staff should be mindful of gender and ethnicity, as well as cultural and religious needs, which may influence the caring role.

Some people who care are relatives, and prefer to use the word ‘relative’ to describe themselves. Others have close friendships and are caring for people who are not relatives. Some do not accept that they are carers or even shun the concept. If someone is involved with and gives significant support to another person irrespective of whether they live with that person or not, they should be considered to be a carer and be actively engaged by the care team.

There may be times when the person living with dementia appears unwilling or unable to acknowledge the carer’s involvement due to their insight, cognitive ability and/or fears about their situation. This needs to be assessed and managed with sensitivity so that an accurate understanding of the situation is gathered. Skill is required in gathering perspectives from both the carer and person living with dementia and assessing insight.

People living with dementia are often vulnerable to abuse and carers need information and knowledge to support the person they care for appropriately. When someone has lost capacity due to cognitive deterioration, a mental capacity assessment must be carried out and the principles of ‘best interest’ decision making understood and adopted which include views of carers.³

³ MCA: Best interests principle | SCIE

‘A carer is anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support’. (Carers Trust, 2022)
Carers can be a mix of relatives including parents, children, siblings, partners or friends. When dementia impacts on the person’s insight or ability to communicate, family and friend knowledge can support the care team to build a relationship with their patient and help them support the person living with dementia to cope – ultimately everyone’s aim.

Recognition and respect are major issues for relatives and friends who provide care, and are central to confident care giving.

“... The staff have to make me feel that I am part of the care and that my husband is definitely part of it, because particularly for people with dementia, it has to be a joint venture.” Unpaid carer

All members of the care team need to know which carer(s) has taken primary responsibility for caring for an individual. This information needs to be recorded. If the person is a parent with a young family, or a young carer, then any pressure on the children in the family needs to be recognised and a referral to young carers services discussed.

Many carers do not recognise they have rights to both information and support. Some may, for example qualify for equipment and financial resources. It is an essential part of a service’s responsibility to promote awareness among carers about their rights.

Practice Examples

What are my rights? | Care For The Carers (cftc.org.uk) (Care for the Carers East Sussex, 2023)

NHS England » Carers toolkit (NHS Carer Toolkit, 2016)

Dementia Statements and rights | Alzheimer’s Society (alzheimers.org.uk) (Alzheimer’s Society, 2023)

2) Staff are ‘carer aware’ and trained in carer engagement strategies.

To support effective delivery of Triangle of Care staff need to understand and appreciate the carers’ perspective. This requires listening empathetically to the experiences and concerns of carers and knowing how to respond. All staff should receive carer awareness training so they understand the impact of caring. They need to be aware of the valuable contribution carers can make to the assessment and care of a person with dementia, be mindful of carers’ own needs and confident when talking to carers.

This does not happen automatically. To help achieve this, staff need knowledge, training and support. They should be capable of dealing with carers’ questions and concerns, and of pointing them towards sources of support. It has been shown to be highly effective to have carers taking part in the planning and delivery of training.

Staff who undertake assessment and care planning should have received specific training in how to involve people with dementia and carers. This needs to include training in communication strategies with people with dementia, thus enabling people with dementia to be engaged for as long as possible.
Successful long-term outcomes are most likely when staff accept the benefits of involvement and collectively promote the concept of a therapeutic triangle formed by themselves, the person living with dementia and carer(s).

“On occasions I have to mediate between specialists, each dealing with a different condition for my husband, without communicating with each other. As a result, not only has there been repetition, confusion and frustration but contradictory treatments which made matters worse and resulted in a measurable decrease in his (my husband’s) wellbeing.” Unpaid carer

Practice Examples

Skills for Care (2023) Dementia (skillsforcare.org.uk) which has a range of resources for staff re good practice.


3) Policy and practice protocols regarding confidentiality and sharing information, are in place.

“Put a group of carers in a room and very soon the issue of confidentiality will come into the discussion.” Carer Support Worker

Confidentiality, though crucial, is often seen as a problem area in creating a Triangle of Care. The therapeutic relationship between the professional and the patient is based on having confidence or trust that what is said will not be disclosed without their agreement.

This agreement needs to be considered in the context that the carer may have key information relevant to safe and effective care planning for the person living with dementia – this is particularly so for those in more advanced stages of the condition or at end of life. They may also be required to take on roles and responsibilities to achieve the best care plan in the home or once the person living with dementia is discharged.

Carers are likely to know the health and wellbeing history of the person living with dementia in detail such as: what has led to their admission to hospital or need for treatment, how their dementia affects them on a day-to-day basis plus how it may affect them during their visit or stay in hospital.

Carers are also aware of what may influence the recovery of the person they care for or know their preferences for end of life care. Carers should therefore be encouraged to share this information, not only because it will help the clinical
assessment and treatment, but also because it gives them a positive role and confidence in the team and wider service.

It is vital to emphasise that confidential information only applies to information that is personal to the person living with dementia, that is identifiable information such as the diagnosis, treatment options and other personal details. Carers can always receive non-confidential information from staff such as information that is already in the public domain about health conditions, the workings of the Mental Health Act (1983) and Mental Capacity Act (2005) and local services available for both carers and people living with dementia. Staff can build stronger relationships with carers by offering and sharing non-confidential information. The Nuffield Council on Bioethics (2009) states that when a person living with dementia lacks capacity to make a particular decision about their health or welfare, it is clearly in their best interests that those involved in making the decision on their behalf have access to the necessary information and are appropriately supported. It recommends that when a person living with dementia lacks capacity to make a certain decision, carers should be provided with any information that it is necessary for them to know in order to carry out their caring role.

**Use of lasting power of attorney and advance directives or plans.**

It is important to establish if the person living with dementia has made an advance plan or directive so that this information is used to inform decisions about care and treatment, especially if the person is reaching end of life.

The carer may also have lasting power of attorney and should be consulted about future and best interest decisions if the person has lost capacity. A number of resources and initiatives are available to support discussions about advance planning and end of life care.

Individual end of life care plans and pathways should be followed which include and involve carers.

**Practice Examples**

SCIE 2019 [Lasting power of attorney – Mental Capacity Act](https://scie.org.uk)

NHS England (2022) [universal-principles-for-advance-care-planning.pdf](https://england.nhs.uk)

**4) Defined post(s) responsible for carers are in place.**

When asked about carers’ issues, some services claim: “All the staff do it!” While it is fundamentally important that all staff should be competent in working with carers, this work needs to be co-ordinated, managed and led.

Ward and team carer links/leads/champions should be appointed. In conjunction with team managers they have the task of promoting carer engagement and overseeing the relationship with carers. It is advisable...
that these leads build strong relationships with their organisation’s dementia leads and champions so they are aware of the complexities involved in caring for someone living with dementia. They need to make sure that measures are in place to support carer involvement and operate effectively. This requires co-ordination by the ward manager or team leader. It is important however, that carer leads do not become a ‘dumping ground’ for carer work – rather that they help co-ordinate the whole-team’s approach to working in partnership with and supporting carers.

Designated carer leads will promote good practice among colleagues, that is, making sure that staff know of any carer involvement in each patient’s care plan and are aware of carers needing orientation to the service or the ward. They can also be the contact between individual carers and staff at meetings and reviews, and can promote carer resources with commissioners. Wards that have appointed a carers lead say that an improved relationship between staff and carers quickly develops.

Carers often find it difficult to monitor their relative’s or friend’s progress or to impart information due to the shift system on wards or community teams’ busy schedules. In addition to the carer lead, teams can appoint a member of staff to act as a carer link for each shift/team. This person would provide additional continuity in receiving and sharing information – and be a clear point of contact.

5) A carer introduction to the service and staff is available, with a relevant range of information across the care pathway.

An introductory letter

When a person living with dementia is admitted into hospital or other care setting, whether as a result of crisis or through planned admission, both the carer and person living with dementia are likely to be anxious about what lies ahead.

The carer may be exhausted and fragile, and not in their most receptive state to receive and retain information. An introductory letter from the named nurse or key worker can help provide reassurance and give both the carer and person living with dementia much needed basic information. This may include names and contact details of key staff and other local sources of advice and support. The carer may then be in a good position to explain information and offer reassurance to the person living with dementia.

An appointment with a named member of the staff team

The letter should also offer an early appointment where the carer can share concerns and family history. Good care planning and accurate assessment can best be achieved with early carer involvement.

A formal appointment should be set up between a carer and member of staff to give the latter a chance to listen to the carer’s story and concerns, and take a good history. The meeting will also give the carer the chance to ask questions in more detail.

Practice Examples

Greater Manchester Mental Health NHS Foundation Trust (2023) Meet Our Carer Champions, Available at: Meet our carer lead and champions | Greater Manchester Mental Health NHS FT (gmmh.nhs.uk)
Ward orientation/carer induction

Many carers argue that admission procedures need to be more carer-friendly, with recognition of the value of carer input and respect for their opinions. Some organisations have created meeting and greeting protocols to help reduce carers’ distress. On arrival, a carer accompanying a person living with dementia should be met, greeted and shown to an appropriate private area where they can discuss in confidence any pressing matters of concern and be offered refreshments.

National guidance and best practice recommends that carers should be given an explanatory leaflet or similar document as part of the admission process, at the time of admission or as soon as possible afterwards. It should include basic information about the ward, what practical items the patient will need in hospital, visiting arrangements, facilities for seeing visitors in private, the roles of involved staff members and how and when they can be contacted.

Some excellent ward leaflets have been produced by staff in collaboration with patients and carers. These leaflets often describe the layout of the building, its facilities and services and basic information about the ward routines.

Some wards produce both a leaflet for patients and one for carers, relatives and friends. Although some information will be common to both leaflets, this approach recognises that the needs of people living with dementia and carers are different and they should be offered different solutions. Information should be accessible and may need to include images or pictures to support understanding.

Carer information packs

Either as part of an initial care plan or as support to the main carer of a person living with dementia, a more in-depth information pack should be provided. This should give carers and families the information needed to understand dementia and other health conditions such as delirium and depression, the likely consequences, what the carer and family can do to help, their rights as carers and the services and support locally available to them and the person they care for.

Carers often begin their journey of caring for someone living with dementia with very limited or inaccurate knowledge of what the illness might mean both for the person they care for and for them as carers. They can be unaware of what resources they may need and where to find them and as result can feel confused, anxious and depressed themselves.

Information about the symptoms of dementia, understanding what to expect and details of local services are also recommended as part of a dementia information prescription or pack for people living with dementia and their carers.

Hospital staff can provide informal verbal support and information, but the provision of a designated information pack also
helps reinforce the central importance of the carer’s role to both carer and staff. It recognises the extent of the knowledge and skill required from the carer and acknowledges their need for support.

Services should have a clear carer care pathway where services check that carers have received this information irrespective of how long they have been a carer or whether they are dealing with a specialist service, inpatient, outpatient or community team.

This may be particularly important for carers from racialised communities and marginalised groups. Steps should be taken to ensure that the cultural and language needs of families or other carers are taken into account in preparing how best to provide carer information.

The ideal pack should be clearly written, well presented and capable of being updated at regular intervals. It should provide local and general sources of support and will need to be flexible and adaptable.

“...The information packs were really useful because I could have a quiet read when I was ready. I could re-read things which were difficult. I keep the pack in an obvious place and it is reassuring to know that there are lots of contacts when I need them.” Unpaid carer

Managing information resources is a challenge to health services and resources need to be up to date, provided in a timely way and used, rather than languishing on some forgotten shelf in the office. These duties are more likely to be done well if they are one staff member’s responsibility. It will help to be clear whether the responsibility for commissioning, storing and issuing the packs lies with a carers lead. Whoever has responsibility, all staff must ensure they know where supplies are and offer/check all carers have or need this information.

Practice Examples

Carer Information Packs – Dementia UK 2023 [Our leaflets – Dementia UK](https://www.dementiauk.org)

Alzheimer’s Society (2023) Caring for a Person With Dementia. Caring for a person with dementia: A practical guide | Alzheimer’s Society (alzheimers.org.uk)

For professionals 2018 [NHS England » Implementation guide and resource pack for dementia care](https://www.england.nhs.uk)

Discharge planning and aftercare support

Planning for discharge should be an integral part of the care pathway and carers are an essential part of this process. Discharge and follow up support must be included in this planning, to achieve the best outcomes.

Co-ordination between the relevant community teams or care home staff, families and carers and the person living with dementia needs to be established before discharge, and the person living with dementia and their carer need to know what support is available and how to access it.
6) A range of carer support services available.

Carer support

The complex and degenerative nature of dementia can have a significant emotional impact on carers with feelings of grief and loss adding to the challenges of their caring role.

All health and social care services should have a carer support service refer to including access to carer advocacy services. Support services may be provided by either the health trust or the local authority social services, third sector or jointly.

Some services have a dedicated worker(s) for the health service overall or a designated link to specific wards. Some supplement this with provision of independent advocacy services, usually managed by local voluntary organisations. Advocacy services should also be offered separately for people living with dementia where available.

All carers should be offered referral to the carer support service. Some may decline for good reasons at that point but their decision should be revisited from time to time.

Carer support posts, or ward or team staff with designated carer responsibilities, should ensure opportunities exist for families and other carers to meet through educational or peer support forums. They may hold carer support meetings which provide the opportunity for mutual support between carers.

While carer group support meetings are much valued, provision for one-to-one support for individuals is also needed. Most carers are likely to have specific and confidential issues which they need to discuss. This can prove difficult if they are part of a group.

Some services use an appointment system to arrange one-to-one support for carers. Having someone to talk to who is well versed in carer issues is an effective way of addressing the stress of being a carer of someone who has become acutely ill.

Carer Support Workers or carer advocates, along with patient advocates, may helpfully attend ward round or review meetings when carers are in attendance and need support.

“It is vital that carers are identified and acknowledged so that they can access the local support services on offer, which will help them care better both for themselves and their loved one. This will help reduce the number of hidden carers in the community.”

Unpaid carer
An assessment of a carer’s own needs

The Care Act 2014 puts in place significant new rights for carers in England. Carers have a right to a carer’s assessment based on the appearance of need and for eligible needs to be met. The Act puts an emphasis on prevention and wellbeing.

The Children and Families Act 2014 gives young carers a right to a carer’s assessment and to have their needs met.

The purpose is to ensure carers’ own needs are recognised and met, and that they are aware of their rights to support, financial and other help in carrying out their carer responsibilities. Carers’ needs assessments are the responsibility of the specific local authority.

Carers may decline the referral for assessment because they are reluctant to discuss their own needs. However, ensuring that the carer’s own needs are identified is not just in the carer’s interests but in the interest of the person they care for and the service as a whole. It is essential that every effort is made to ensure carers receive all the support they are entitled to, given that they will often have the primary responsibility for assisting the person with dementia once they have left hospital or when they are not receiving formal support. Staff should confirm that the carer is aware of the right to an assessment, and, if necessary, refer them.

It is rarely sufficient to carry out a carer’s needs assessment in a one-off interview. This may be the first occasion when the carer’s interests have been addressed and their primary need may be to offload and explore better care for the person they care for, rather than their own needs. As rapport and confidence in the process develop there will be a more meaningful exchange of information and insights. As individual needs are met during the assessment process, carer confidence should increase.

Practice Examples


The Care Act 2014 Care Act 2014 (legislation.gov.uk)
Regular assessments and audits must be undertaken to ensure the six key standards of carer engagement are in and remain in place.

The Triangle of Care approach has been developed from the experience of scores of carers who say that too often some or all of the key standards are not in place and from the good practice of those services striving to create an effective partnership with carers.

Reviewing current practice and benchmarking where you are

The first stage for a local health service wishing to review its practice is to take stock of the current situation and to develop a plan to put all the required standards in place. This exercise should be undertaken with local carers (and people living with dementia) to benchmark and identify any areas that carers regularly report as problematic, and to get their ideas on what is most needed. To help, we have included a simple self-assessment benchmarking checklist that uses the Red, Amber, Green analysis tool.

Regular auditing

The second stage is to regularly re-assess to ensure that the six key standards are in place and are working well. Only by a system of regular feedback from carers themselves will services be able to know how well they are operating a Triangle of Care approach. It is important to look across the entire care pathway to get a clear overview of the whole process and any weak spots.

Practice Examples

SCIE (2020) Evaluating personalised care - SCIE

NICE (2020) Supporting Adult Carers – Tools and Resources, Audit and Service Improvement, Baseline Assessment Tool, Available at: Tools and resources | Supporting adult carers | Guidance | NICE.
The Triangle of Care Membership Scheme is a three-stage recognition process for services in health and care who commit to self-assessing their existing services and develop action plans to support the achievement of the Triangle of Care.

The Triangle of Care is a partnership between patients/service users, staff members and unpaid carers. This alliance promotes safety, supports communication and sustains wellbeing.

The stages of the Triangle of Care are:

1. Completing star one (self-assessing all inpatient and crisis teams) and then committing to improve.

2. The second star is for completing self-assessments for all community services. This is all mental health, learning disability, older people and dementia and substance misuse services.

3. Providers which are integrated (community physical health services), receive a third star if they complete self-assessment in all of their physical health services.

For further information and resources go to The Triangle of Care or contact TriangleofCare@carers.org
Better engagement by health services with people living with dementia and carers as active partners is a necessary underpinning of more effective planning and delivery of health care.

The implementation of the six key standards will mean carers feel the contribution they can make is adequately recognised and their expert knowledge is properly taken into account.

Carers provide an enormous amount of care in the community for people living with dementia. The ongoing development of home based care at times of acute illness is further evidence of the need to give considerable attention to the views and needs of carers. The shift of care from hospital to home, as well as virtual wards can mean much greater reliance on carers, with a consequent impact on their lives and a greater need for engagement and support.

Developing the Triangle of Care model may require some investment in staff training and practical support for carers. Benefits can most importantly include better quality care outcomes, but also more cost effective service delivery through decreased admission rates and reduced length of stay.

Having a Triangle of Care in place will ensure the views of carers in formulating care plans and policy is translated into their inclusion at all levels of the process and their often crucial role is supported through practical means.

Services for carers

In some locations, services for carers may be provided by voluntary organisations and sometimes these also manage care support workers. All front line staff should make themselves aware of their local carer support provision and other services. Carers Trust network of carer support organisations can be found here.