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Royal College of Nursing

Triangle of Care

The Triangle of Care

Carers Included: A Guide to Best Practice for Dementia Care

Kindly supported by

RCN Foundation

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 Royal College of Nursing Foundation Grants Programme, the recent development of a Triangle of Care for dementia has been a collaborative effort between the Royal College of Nursing and Carers Trust. It has been co-designed with carers, people with dementia and practitioners, with the support of Uniting Carers and Dementia UK.

We acknowledge the thought and effort which has gone into creating the best practice examples and are grateful for the generosity of carer and dementia champions in responding to requests to make them widely available.

The development of a new Triangle of Care for dementia has been developed in recognition of the need to improve carer involvement in hospital settings, but its application is relevant across all settings.

We would like to thank Alan Worthington and Malcolm Rae who have generously offered their experience and support. Thanks also to Joy Watkins and Nikki Mills for facilitating and co-ordinating the workshop that informed this resource.

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Foreword

When Carers Trust was approached by the Royal College of Nursing to explore whether our Triangle of Care project could be adapted to meet the needs of carers of people with dementia in acute hospitals we were delighted. This collaborative project has developed through the support of carers, people with dementia and professionals.

The Triangle of Care model of carer inclusion and support has proved to be very successful in mental health services with over three quarters of mental health providers in England involved in the project and the model being adapted for use in Scotland and Wales.

We hope the new guide for best practice in dementia care can lead to consistent carer involvement and support across all health and social care services irrespective of where and when a person is being treated.

The partnership between Carers Trust and the Royal College of Nursing has been incredibly positive and we hope that this can be replicated across health services with nurses and carers working as partners.

Thea Stein, Chief Executive, Carers Trust

About Carers Trust

Carers Trust is a major new charity for, with and about carers. We work to improve support, services and recognition for anyone living with the challenges of caring, unpaid, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems.

We do this with our Network Partners – a unique network of independent carers centres, Crossroads Care schemes and young carers services. Together we work as one organisation united by a shared vision for carers – to make sure that information, advice and practical support are available to all carers across the UK.

About the Royal College of Nursing Foundation

The Royal College of Nursing Foundation was set up in 2010 to support nursing staff to improve the health and wellbeing of the public. It funds bursaries for those wishing to study and provides support to staff at times of hardship. It also provides grants to nursing led innovative projects that make a difference to service development and that will improve the safety, quality and dignity of patient care.

"We are proud to support the partnership work of Carers Trust and the Royal College of Nursing. We are sure that the Triangle of Care is a resource that will help support an inclusive approach to providing good quality care for people with dementia and their carers."

Dinah Cox, Head of Royal College of Nursing Foundation

Executive summary

The Triangle of Care describes a therapeutic relationship between the person with dementia (patient), staff member and carer that promotes safety, supports communication 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 with dementia. In an ideal situation the needs of the carer and the person with dementia are both met. Inclusion of people 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 with dementia, carers and practitioners. Including and supporting carers of people with dementia will lead to better outcomes for patients, carers and ultimately the professionals supporting them (Royal College of Nursing, 2013).

While developed with dementia in mind the standards are applicable for anyone caring for or living with someone with a long-term health condition.

"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 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."

Carer

The key standards to achieving a Triangle of Care

This guide identifies six key standards required to achieve better collaboration and partnership with carers.

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

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.**

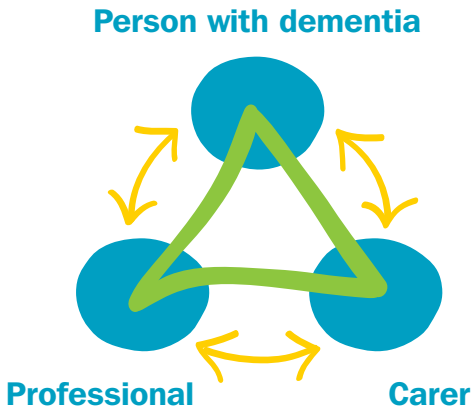
3) **Policy and practice protocols regarding confidentiality and sharing information, are in place.**

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 Appendix 1.



Who is this document for?

This guide is primarily addressed to those involved in the care of people 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 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 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.

Commissioners, providers of services and Care Quality Commission assessors need to recognise that supporting carers through initiatives such as the Triangle of Care is a sound investment in safety, quality and continuity of care at relatively little financial cost. However, carer support should not be seen as a means to reduce support to people with dementia or to legitimise inappropriate assumptions from services about how much carers can take on.

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. We have also included some practice examples from across the UK.

Introduction

The Triangle of Care was developed in mental health services and Carers Trust is currently working with mental health providers to implement the Triangle of Care in their services. For more information go to: **http://professionals.carers.org/health/articles/triangle-of-care,6802,PR.html**

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: a carer engagement approach for services supporting people with dementia

The Triangle of Care for Dementia has built on the original guide – The Triangle of Care: Carers Included: A Guide to Best Practice in Acute Mental Health Care (The Princess Royal Trust for Carers, 2010) – and applies the same standards to services caring for people with dementia. While this guide has a focus on general hospitals, 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 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.

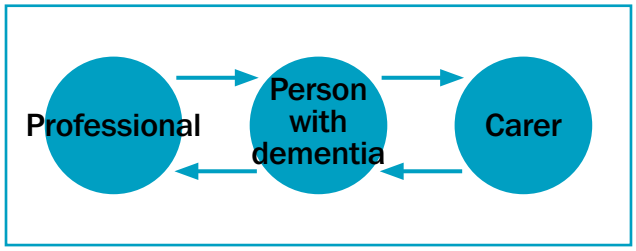
Carers can help in a number of ways including:

- **Providing valuable information and history.**
- **Communicating with the person with dementia.**
- **Offering support and reassurance to the person 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 with dementia and those caring for them. While the person with dementia has capacity they must be supported to make their own decisions and articulate views. However, if they lack capacity, health and social care professionals must act in the 'best interests' of the person 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 with dementia is essential within this.

The Triangle of Care for Dementia builds on the concept of relationship centred care which, as highlighted within guidelines for dementia, emphasises "the importance of relationships and interactions with others to

the person with dementia, and their potential for promoting well-being in the delivery of person-centred care." (NICE/SCIE, 2006).



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 with dementia and the carer.

Some common problems

"Once, I stepped away for one hour, after seven hours in A&E, and Mum was discharged during that hour on the basis that she'd given the answer "three months" to a question about the start of symptoms whose real answer was '7 o'clock this morning' – even though the notes had all the information in them and my contact details were in the notes."

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."

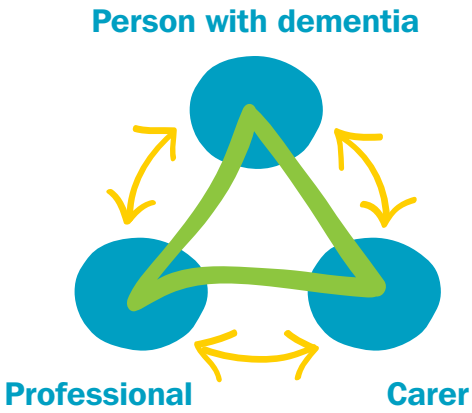
Carer

"On visiting my husband in hospital, I would often find him sat with cold food and drink left untouched as he didn't know how to deal with it. If they had let me visit outside visiting times I could have helped him, but I often couldn't find anyone to talk to about it. "

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 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 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 with dementia is included in decision making. This requires an understanding of dementia and skill in how to support communication for people 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."

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.

Why is carer engagement so important in dementia care?

"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."

Carer

Carers have a crucial role to play in the care of people with dementia. When a person 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 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.

Carers of people with dementia also have their own needs, which need to be assessed and taken into account. Research shows that carers of older people with dementia experience greater strain and distress than carers of other older people (Moise, Schwarzinger, Um, 2004). In addition, many carers of people with dementia are older people themselves, with physical frailty and health conditions of their own (The Princess Royal Trust for Carers, 2011).

It is carers who are responsible for care when the professionals aren't there, and as the condition progresses are commonly faced with co-ordinating 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 with dementia

Best practice examples

- **Recognised, Valued and Supported: Next Steps for the Carers Strategy (Department of Health).**
- **National Dementia Strategy (Department of Health).**
- **Dementia; Workers and Carers Together (Skills for Care/Dementia UK).**
- **Hello I'm Me** and **Hello I'm Still Me (University of Worcester, NHS Gloucestershire and Gloucestershire County Council)** – Booklets written by June and Brian Hennell (carer and person living with dementia) to describe impact of dementia on both people.

Admission to hospital can be very distressing for people with dementia but it is also a time when carer engagement needs to be given special attention.

"When my mother was admitted to hospital in an emergency I sought to ensure the doctors and nurses recognised me as her carer, otherwise there was a serious danger they would cause her distress if they asked her lots of questions in my absence."

Carer

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.

Best practice example

- **www.dyingmatters.org** – website raising awareness of end of life good practice.

Supporting carers in hospital

Involvement of carers can be a particular issue within inpatient services. The National Audit of Dementia report (Royal College of Psychiatrists, 2013) recommended improvements in the way carers are involved in assessment, care planning and decisions about discharge.

Hospital case study

In October 2009, St Helens and Whiston hospital became a Department of Health project site, designed to improve NHS support for carers. A service was designed and delivered to identify carers in the hospital and then refer carers to a service for advice and support. The Carer Support Officers work across both hospital sites to support people who are in a caring role. They have time to speak to carers about concerns and worries as well as speaking on behalf of the carer on discharge planning and to raise issues that are causing a delay to discharge.

Creating the Triangle of Care

In the Triangle of Care you will find ways of achieving better collaboration between the clinician/team/ward, person 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."

Carer

The key standards 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 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 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 with dementia.
   - Staff need knowledge, training and support to become carer and dementia aware.

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

   To ensure proactive engagement carers need to be part of care planning and treatment and 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 with dementia, carer and professional – which includes assessment of capacity and best interests 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 champions 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 the carers' views and involvement.
- Ward 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.
- Carer needs assessment.
- Mechanisms for gathering feedback which are used to inform service improvement.

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

A self-assessment audit tool for carer engagement can be found in Appendix 1.

The rationale behind the key standards

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

Staff need to identify who the carer(s) is, that is the person who is providing significant support, their relationship with the person 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 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.

Who are carers?

The term carer is relatively new in health and social care, though the concept of what a carer is or does is more widely understood. 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 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 with dementia and assessing insight.

People 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. See **www.bestinterests.org.uk**.

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's and friend's knowledge can support the care team to build a relationship with their patient and help them support the person 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."

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.

Best practice examples

- **Carers Charter (Greater Manchester West NHS Foundation Trust)** – Sets out what carers can expect from services.
- **Caring Together (Nottingham University Hospital)** – A form for carers of people with dementia to complete when that person is admitted to hospital.

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

Do all front line staff understand "being in the carer's shoes"?

To support effective delivery of a 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 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."

Carer

Best practice examples

- **Pathway for Carers (St Helens and Knowsley NHS Teaching Hospital).**
- **The Butterfly Scheme** – Encourages staff to use a carer sheet as well as helping staff to understand the carer perspective. **www.butterflyscheme.org.uk**
- **Carers Passport (Kingston Hospital)** – A passport is given to carers to acknowledge their role and allow them flexible visiting.

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 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 with dementia is discharged.

Carers are likely to know the health and wellbeing history of the person 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.

Staff need to understand 'the confidentiality principle' that is:

"Information provided or discovered in the course of the professional relationship cannot be disclosed without consent. … The service user does not have the right to prohibit a professional from engaging with a carer or from the carer being given information, advice and support, nor from talking to the carer about the patient, provided that no confidential information is divulged … Confidential information may be disclosed with the service user's consent, (express or implied), regarding specific information and to specific individuals."

(Machin, G, 2012)

The Caldicott Principles

The Caldicott Principles, which set out how health and social care should balance sharing personal information and protecting an individual's confidentiality, have recently been reviewed and an additional seventh principle added which clarifies the value of sharing information

Principle 7: The duty to share information can be as important as the duty to protect patient confidentiality.

(Department of Health, 2013)

It is vital to emphasise that confidential information only applies to information that is personal to the person 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 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 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 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.

Similarly, carers have the same rights to confidentiality of information they disclose as the people they care for do. It is vital for staff to understand and respect carers' rights as they would patients'.

Best practice examples

- **Carers and Confidentiality in Mental Health (Royal College of Psychiatrists and The Princess Royal Trust for Carers)** – A short leaflet for staff working with carers.
- **Common Sense and Confidentiality (Northumberland, Tyne and Wear NHS Foundation Trust)** – A guide for carers on how information will and can be shared in the mental health trust.
- **Mental Capacity Act 2005. Code of Practice (Office of the Public Guardian)** – A guide for carers on the Mental Capacity Act 2005.

Use of lasting power of attorney and advance directives or plans

It is important to establish if the person 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.

Best practice examples

- **Difficult Conversations for Dementia (National Council for Palliative Care/ Dying Matters)** – Booklet to help initiate conversations about advance planning and end of life care.
- **Preferred Priorities for Care (NHS National End of Life Care Programme)** – Document which can be used to help record preferences and decisions for end of life care.
- **Capacity, Care Planning and Advance Care Planning in Life Limiting Illness: A guide for Health and Social Care Staff (NHS National End of Life Care Programme)**
- **Our Plan; Planning the Journey (NHS Surrey)** – A practical resource for family and carers of people with dementia in planning for future care.
- **National Gold Standards Framework provides information and resources to support good end of life care. www.goldstandardsframework.org.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 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.

Best practice examples

- **Carer Champion (Somerset Partnership NHS Foundation Trust).**
- **Carer Lead (Avon and Wiltshire Mental Health Partnership NHS Trust).**

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 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 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 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 with dementia.

Best practice example

- **Carer's Initial Care Plan Letter (Avon and Wiltshire Mental Health Partnership NHS Trust).**

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.

Best practice example

- **Initial Family Liaison Meeting (Somerset Partnership NHS Foundation Trust)** – A process whereby carers are offered an initial meeting.
- **Getting to Know You (Northumberland, Tyne and Wear NHS Foundation Trust)** – A process whereby carers are offered a meeting within 72 hours.

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 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 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 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 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 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 black, Asian and minority ethnic communities. 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."

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.

Best practice examples

- **Dementia Information Prescription** – Information about local services for people with dementia and their carers in Bath and North Somerset. **www.dementiaweb.org.uk**
- **Create your own Information Prescription through NHS Choices. www.nhs.uk/pathways/dementia**
- **Information Leaflet for People with Dementia and their Carers (Kingston Hospital).**
- **Understanding Dementia – Living well with Dementia; Information for Patients and Carers (Southampton University Hospital).**
- **Dementia Carers' Pathways (REPoD)** – Booklet developed by carers in Devon.

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 with dementia needs to be established before discharge, and the person with dementia and their carer need to know what support is available and how to access it.

Best practice example

- **Carer Involvement in Assessment and Discharge Planning (Betsi Cadwaladr University Health Board).**
- **Information leaflets for carers on dementia, delirium and discharge planning (Nottingham University Hospital).**

6) A range of carer support services is 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 in place, 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 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."

Carer

Best practice examples

- **Carers' Hub (Carers Trust)** – Commissioning guidance to ensure carers receive the support and recognition they deserve. **www.carershub.org**
- **Carers Champions: Carrying out Carers' Assessments (Basildon and Thurrock NHS Trust).**

An assessment of a carer's own needs

If the carer provides a lot of care and support to the person with dementia, they are entitled by law to a carer's assessment. (Carer's (Recognition and Services) Act, 1995, amended by Carers and Disabled Children Act 2000, Carers (Equal Opportunities) Act 2004).

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.

Best practice examples

- **The Carers support group at New Cross Hospital (Royal Wolverhampton NHS Trust)** – Run by carers and healthcare professionals, it offers a forum for carers to meet other carers, speak with professionals and be signposted to relevant services within their local area. **www.royalwolverhamptonhospitals.nhs.uk/patients__public/information_for_patients/patient_support_groups.aspx**
- **Carer's cafe (University Hospital Southampton)** – Admiral Nurse service provides a support group for carers of people with dementia who are visiting in hospital.
- In Lothian, a range of support services including information and support for carers and people with dementia are on offer. **https://dementia.stir.ac.uk/files/GoodPracticeInLothian.pdf**

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 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 (see Appendix 1).

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.

Best practice examples

- **Carer Questionnaire Letter (Tees, Esk and Wear Valleys NHS Foundation Trust)** – A letter inviting carers to give feedback on their experiences of people with dementia who have been admitted to a general hospital.
- **Kingston Hospital Carers Survey** – This brief questionnaire gathers feedback about how to improve support for carers.
- **1000 Lives Plus – Improving Dementia Care** – Recommends regular data collection to ensure involvement in care planning, the offer of an assessment and information sharing in Wales. It also provides a carer's questionnaire to gather feedback. **www.1000livesplus.wales.nhs.uk/mh-dementia**

Triangle of Care membership scheme

Since the launch of the original Triangle of Care guide (The Princess Royal Trust for Carers, 2010), the project is now working with over three quarters of the trusts offering mental health services in England; in addition work on the Triangle of Care has begun in Scotland. The project supports mental health service providers to work to achieve the six standards of the Triangle of Care through regional events and meetings.

In October 2012, Carers Trust launched a formal membership scheme enabling mental health trusts who are working on completing the self-assessment tool across their organisations to achieve recognition of this. More information on the membership scheme can be found at **http://professionals.carers.org/health/articles/triangle-of-care,6802,PR.html**.

At present, the scheme is only available to mental health providers, although this may change in the future.

Closing comments

Better engagement by health services with people 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 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 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 Carers Support Workers. All front line staff should make themselves aware of their local carer support provision and other services.

Appendix 1: Triangle of Care self-assessment tool

Tips and Guidance for staff completing the self-assessment tool

The Triangle of Care self-assessment tool enables health providers to assess their services on a ward by ward or team by team basis.

The tool is easy to use and involves a simple traffic light system for assessing service delivery.

Guidance notes have been developed as a result of feedback from members of the Triangle of Care Steering Group who have begun to assess their services.

General guidance

- **Consistency** – although individual units and teams can complete the self- assessment; it is recommended that all teams complete the tool at the same time as a co-ordinated exercise. Ideally, completed self-assessments are sent to an independent person (ward manager or carer lead) to review. The review should check the ratings and action points are consistent. This will also enable identification of common issues across teams, identify good practice and share this across the organisation.
- **Honesty and candor** – adopting this principle will benefit the organisation or team when completing the self-assessment. Staff who have completed the tool previously have found it a more positive experience to adopt a warts-and-all approach. This enables teams to see what they are doing well and be able to action plan more clearly for areas that require improvement. No team or ward is expected to be perfect and some deficits are to be expected. It is crucial to convey to teams that these deficits will not be punished and it is recommended that a league table system is not adopted.
- **Traffic light ratings** – there is an expectation that when awarding a green traffic light the team should have over 80% success rate. An amber traffic light requires 50% or over.
  - For example: **criteria 1.1 identifying the carer routinely**; this should be occurring with 80% or more of carers.
  - Another example is **criteria 2.1 staff have received carer awareness training**; this should be when 80% of staff have either received the training or are booked on to it and when the training is up to date and relevant. Crucially, this 80% must include the most senior staff on the ward/team including consultants.
- **Clarity** – to ensure accuracy it is advised that figures used are evidenced, for example checked against training records.
- **The By whom Section of the form** – this section should include the name of the person completing the form; if this is not a senior member of staff then they must counter-sign. It may also be beneficial to include the name of the person who will be responsible for this area as this gives the whole team responsibility for the project.

Finally …

Once completed, the self-assessment tool should be reviewed with the entire team it refers to. From this point an action plan should be developed demonstrating how improvements will be made and a set timeframe for this action plan put in place. At the end of this time the self-assessment tool should be completed again to assess how and where improvements have been made.

Triangle of Care Self-assessment Tool

This tool is suitable for all services, however there may be words and phrases that are not used in your specific service. If so, you will need to adapt the tool to meet your organisation's needs.

This tool uses the Red Amber Green system to assess the current situation for each point.

Standard 1 – Carers and their essential role are identified at first contact or as soon as possible afterwards

	Criteria	R	A	G	Where are we now?	Action plan	Evidence of achievement	By whom?	By when?
1.1	Processes are in place to establish whether a carer is involved, the main carer is identified and agreed named contacts are recorded in the notes. (Where there is no immediate carer involved, information is sought about significant others who may support the person, for example neighbours or other services).								
1.2	The person with dementia is consulted about involvement of the carer, unless this is not possible.								

(continued)

Standard 1 – (continued)

	Criteria	R	A	G	Where are we now?	Action plan	Evidence of achievement	By whom?	By when?
1.3	The main carer or carers are routinely identified and their views sought within the assessment process to help inform care.								
1.4	An assessment of carer needs is carried out.								
1.5	Processes are in place to ensure that information is shared with all practitioners involved in care, including those supporting other co-morbid conditions, to avoid conflicting treatments.								
1.6	A record is made of lasting power of attorney(ies) and whether an advance plan and/or directive is in place.								
1.7	People with dementia **and their carers** are regularly updated and involved with care plans and treatment which focus on all their needs.								

(continued)

Standard 1 – (continued)

	Criteria	R	A	G	Where are we now?	Action plan	Evidence of achievement	By whom?	By when?
1.8	Advice about advocacy, information and support services are made available to both the carer and the person with dementia.								

Standard 2 – Staff are carer aware and trained in carer engagement strategies

	Criteria	R	A	G	Where are we now?	Action plan	Evidence of achievement	By whom?	By when?
2.1	All staff have received training about the needs of carers and their relationship with the person with dementia, and know how to work in partnership.								

(continued)

Standard 2 – (continued)

	Criteria	R	A	G	Where are we now?	Action plan	Evidence of achievement	By whom?	By when?
2.2	The training includes: • Understanding of carers needs and how these relate to the person with dementia. • Carer expectations about assessment, treatment and support. • Dealing with carer queries and concerns. • Advising on sources of help and support. • Advising on treatments, approaches to care and managing medicines. • How to involve carers and people with dementia in the delivery of care, including at the end of life. • Balancing differing needs of people with dementia and their carers.								
2.3	Training involves the perspectives of both carers and people with dementia.								

Standard 3 – Policy and practice protocols regarding confidentiality and sharing information, are in place

	Criteria	R	A	G	Where are we now?	Action plan	Evidence of achievement	By whom?	By when?
3.1	Consent is sought from the person with dementia to share confidential information with the carer(s), wherever possible.								
3.2	Decisions about sharing information with the carer are based on an assessment of capacity and best interest decisions.								
3.3	Practice guidelines about information sharing with carers are in use.								
3.4	Lasting power of attorney and advance directives or plans are routinely used where they are in place.								
3.5	Carer's assessment, notes and letters are kept in a separate section of the patient's notes.								

(continued)

Standard 3 – (continued)

3.6	Discharge procedures routinely include carers' wishes or preferences about future care, including consideration of whether carers' wishes and those of the person with dementia are different.								

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

	Criteria	R	A	G	Where are we now?	Action plan	Evidence of achievement	By whom?	By when?
4.1	Ward sister or manager is responsible for ensuring carer involvement by all staff.								
4.2	Carer leads/champions are in place and have an understanding of dementia.								
4.3	Carer leads/champions work closely with local dementia champions to provide support for carers.								

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

	Criteria	R	A	G	Where are we now?	Action plan	Evidence of achievement	By whom?	By when?
5.1	On initial contact with services, the carer and person with dementia are given an introductory letter that explains the service and points of contact.								
5.2	An information pack, which explains practical matters, how to get involved, carer support, information about discharge and support services, is made available.								
5.3	Policies and procedures about carer involvement and information about carer support are made readily available and clearly advertised.								
5.4	Meeting and greeting protocols are in place for carers to offer support, reduce distress and address concerns.								

(continued)

Standard 5 – (continued)

	Criteria	R	A	G	Where are we now?	Action plan	Evidence of achievement	By whom?	By when?
5.5	Carers are offered an early appointment to hear their story, share information about the person they care for and address concerns.								
5.6	The cultural and language needs of carers has been addressed in the preparation of the information pack.								
5.7	The format of the information pack is flexible and regularly updated.								
5.8	A member of ward or team is made responsible for commissioning, storing and issuing the packs.								
5.9	Staff offer carers the opportunity to have a conversation and encourage them to access support.								
5.10	The carer is involved in the discharge planning (either from the ward or if in the community, from secondary services) process and is clear about what to do if, for example in need of help.								

(continued)

Standard 5 – (continued)

	Criteria	R	A	G	Where are we now?	Action plan	Evidence of achievement	By whom?	By when?
5.11	The carer is asked for feedback regarding the service provided as part of service monitoring and improvement.								

Standard 6 – A range of carer support is available

	Criteria	R	A	G	Where are we now?	Action plan	Evidence of achievement	By whom?	By when?
6.1	Dedicated peer and carer support services are available locally.								
6.2	Local advocacy services are available for carers and people with dementia.								
6.3	Carer has access to one-to-one support when needed.								
6.4	Need for support on discharge is discussed with the carer and the person with dementia.								

(continued)

Standard 6 – (continued)

	Criteria	R	A	G	Where are we now?	Action plan	Evidence of achievement	By whom?	By when?
6.5	A new carer is automatically offered a carer's assessment and support plan which includes the need for support, and identifies any areas of risk.								
6.6	A referral is made to local services for carer support where required.								

References

The best practice examples cited in this document can be found on the Royal College of Nursing dementia pages at **www.rcn.org.uk/development/practice/dementia/best_practice_examples**.

The Virtual Ward (a good practice repository) also offers a wealth of other good practice examples at **www.rcn.org.uk/development/mental_health_virtual_ward/carers_and_families**.

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Additional resources

Commissioning for carers (Carers Trust)
www.carershub.org

Dementia Partnerships
www.dementiapartnerships.org.uk

Dying Matters Campaign
http://dyingmatters.org

Royal College of Nursing
www.rcn.org.uk/development/practice/dementia

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