



The Triangle of Care

Carers Included: A Guide to Best Practice for Dementia Care in Scotland

Kindly supported by



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.

The original version of this guide was funded through the RCN Foundation Grants Programme. The recent development of a Triangle of Care for carers of people with dementia has been a collaborative effort between the Royal College of Nursing and Carers Trust.

To reflect the Scottish context, the Triangle of Care has been adapted to suit the Scottish legislation, initiatives and policies around dementia. This Scottish version has been a collaborative effort between Carers Trust Scotland, Royal College of Nursing Scotland, NHS Greater Glasgow & Clyde, University of Stirling Dementia Services Research and Dementia Carers Voices.

We acknowledge the thought and effort which has gone into creating the best practice examples and are grateful for the generosity of carers, Dementia Champions and colleagues in the NHS, workforce education and dementia services in responding to requests to make them widely available.

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

Authors

Ruth Hannan – Carers Trust

Rachel Thompson – Royal College of Nursing
Alan Worthington, Carer Advisor to The Triangle of Care: Carers Included: A Guide to Best Practice in Acute Mental Health Care (The Princess Royal Trust for Carers, 2010)

Paul Rooney, National Acute Care Programme, Advisor to The Triangle of Care: Carers Included: A Guide to Best Practice in Acute Mental Health Care (The Princess Royal Trust for Carers, 2010)

Additional authors on this edition

Karen Martin – Carers Trust Scotland

Helen Richens – Royal College of Nursing Scotland

Myra Lamont – Carer (and member of Alzheimer Scotland's National Dementia Carers Action Network)

The development of the original guide was kindly funded by the Royal College of Nursing Foundation.

Published by
Carers Trust Scotland
Suite 1/2
Skypark 3
14–18 Elliot Place
Glasgow G3 8EP
Tel: 0300 123 2008
Fax: 0141 204 3769
Email: scotland@carers.org
www.carers.org
<http://professionals.carers.org>
www.carershub.org

Carers Trust is a registered charity in England and Wales (1145181) and in Scotland (SC042870). Registered as a company limited by guarantee in England and Wales No. 7697170. Registered office: 32–36 Loman Street, London SE1 0EH.

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Foreword

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.

This publication has been adapted from *The Triangle of Care: Carers Included A guide to Best Practice in Dementia Care*, which was funded by the RCN Foundation.

“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.”

Moira Fraser,
Interim Chief Executive Carers Trust

“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

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 are united by a shared vision for carers – to make sure that quality assured information, advice and practical support are available to all carers across the UK.

Our vision is of a world where the role and contribution of **unpaid** carers is recognised and they have access to the trusted quality support and services they need to live their own lives.

About Royal College of Nursing Scotland

Royal College of Nursing Scotland is a professional body and trade union for nurses and health care support workers with around 39,000 members in Scotland. The Royal College of Nursing represents nurses and nursing, promotes excellence in practice and shapes health policies.

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.

The Triangle of Care describes how meaningful involvement and inclusion of carers can lead to better care for people with dementia. The Royal College of Nursing project Dignity in Dementia: Transforming General Hospital Care (2011) highlighted that involving carers was highly instrumental in supporting improvement in care, and was seen as a high priority by people with dementia, carers and practitioners.

The Scottish Government and health and social care providers have long recognised the importance of carers as equal partners in care. Caring Together, the Carers Strategy for Scotland 2010–15 (Scottish Government, 2010) and the joint NHS Education for Scotland and Scottish Social Services Council project Equal Partners in Care emphasises how carers are equal partners in the planning and delivery of care and support (NHS Education for Scotland and Scottish Social Services Council, 2013).

The Triangle of Care complements existing policies designed to improve care for people with dementia in Scotland. In particular, it supports the Scottish Government’s commitment to “work as equal partners with families, friends and carers” in the 10-Point National Action Plan, in Scotland’s National Dementia Strategy, and the implementation of commitment 11 to extend the work on quality of care in general hospitals to other hospitals and NHS settings (Scottish Government, 2013). The Standards of Care for Dementia in Scotland are clear that carers need to be recognised, valued and supported in their role as partners in care. This is underpinned by the Promoting Excellence Framework that sets out the knowledge and skills all health

and social services staff should achieve to support and involve people with a diagnosis of dementia, and their families, and carers. The Charter of Rights for People with Dementia and their Carers in Scotland (Cross Party Group on Alzheimer’s, 2009) was developed to ensure that human rights of those living with dementia, their families and carers, are recognised and respected by society.

The Triangle of Care for Dementia is a practical tool to help staff put these overarching policies into practice. The self-assessment audit tool will help staff demonstrate how they are meeting the dementia standards and the Promoting Excellence Framework. Together, this will drive forward the Scottish Government’s commitment to work as equal partners with families, friends and carers.

“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

Charter of Rights for People with Dementia and their Carers in Scotland

(Cross Party Group on Alzheimer’s, 2009)

The Triangle of Care supports the rights of people with dementia, their families and carers. The Triangle of Care is one tool which can be used to ensure that these rights are recognised and respected as follows:

(continued)



Participation, including rights to accessible information and support to participate in decisions that affect them; to live as independently as possible with access to community facilities; to full participation in planning care; and to be assisted to be involved in policy making.

The Triangle of Care was developed as a tool to assist full participation of the person with dementia, their carer and staff in all aspects of care and treatment, including participation in policy decision making and service design.

Accountability, including rights to enjoy human rights and fundamental freedoms including full respect for the dignity, beliefs, individual circumstances and privacy of the person with dementia and their carer; and to the accountability of organisations and individuals responsible for care and treatment for the respect, protection and fulfilment of their human rights.

The framework of the Triangle of Care ensures that those responsible for care and treatment do so in a manner which is respectful of the human rights of those living with dementia and their carers, in particular the standards around confidentiality, sharing information, carer awareness and providing a range of support for carers.

Non-discrimination and equality, including rights to be free from discrimination based on grounds such as age, disability, gender, race, sexual orientation, religious beliefs, social or other status.

The Triangle of Care is based on the belief that carers, those living with dementia, and staff should work in equal partnership to provide best care and treatment outcomes for carers and people living with dementia, regardless of age, disability, gender, race, sexual orientation, religious beliefs, social or other status.

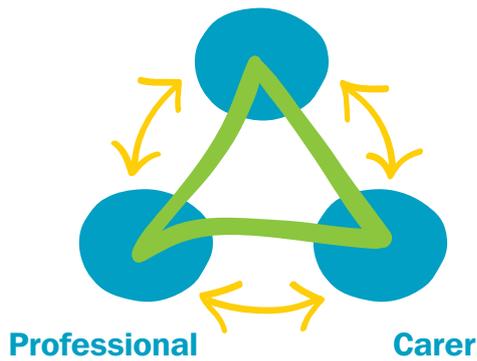
Empowerment, including rights to appropriate levels of care providing protection, rehabilitation and encouragement; to help to maintain maximum independence, physical, mental, social and vocational ability and full inclusion and participation in all aspects of life; to access social and legal services to enhance the autonomy, protection and care of the person with dementia and their carer; and health and social care services provided by people with appropriate training on dementia and human rights.

The Triangle of Care process is centred around staff being 'carer aware' and this includes understanding the needs of dementia carers, their rights to access services to help with their caring role, and their right to a quality of life outside their caring role.

Legality, including rights to have the full range of human rights respected, protected and fulfilled, regardless of diagnosis; to information, participation in decision making and the appropriate remedies; and where someone lacks capacity to take a specific action or decision, the requirement that anyone acting for them has regard for the principles and provisions of the Adults with Incapacity (Scotland) 2000 Act.

The Triangle of Care standards place emphasis on the principle of confidentiality and the rights of the person living with dementia to confidentiality, sharing of agreed information, and support to make decisions where someone lacks capacity. The Triangle of Care has regard for the principles and provisions of the Adults with Incapacity (Scotland) 2000 Act, and the underlying principles of the Mental Health (Care and Treatment) (Scotland) Act 2003 to ensure that those carrying out any duties within these legal provisions do so with regard to the rights of the person with dementia and their carers.

Person with dementia



Who is this guide for?

This guide is primarily addressed to those involved in the care of people with dementia in hospital settings, though the principles are applicable across health and social care settings. It is primarily for frontline staff and their managers working in health, social care and third sector services, though the principles are applicable to commissioners and providers of services. It can also be used to inform carers, people with dementia and carer groups.

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.**

The principles within the Triangle of Care are also relevant to the wider organisations that have a role in supporting people with dementia, including NHS health boards, local authority providers, NHS Education for Scotland, Healthcare Improvement Scotland, Scottish Social Services Council and the Care Inspectorate. Supporting carers through initiatives such as the Triangle of Care enhances care for people with dementia, and 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.



Introduction

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

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 behaviour and general wellbeing.
- Provide peace of mind for carers that the person they care for is receiving the best and appropriate treatment possible.

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

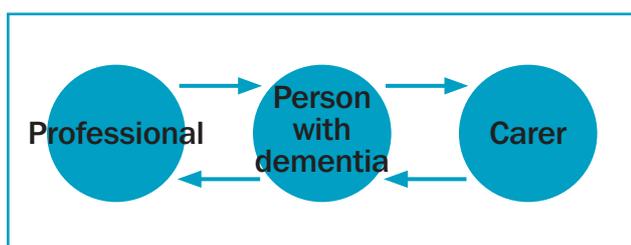
Dementia is a degenerative condition which can affect a person’s insight, capacity and ability to make decisions. This can result in differing views and needs between people with dementia and those caring for them. While the person with dementia has capacity they must be supported to make their own decisions 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 Adults with Incapacity (Scotland) Act (2000). Balancing the needs and views of carers with those of the person with dementia is essential within this.

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, Schwarzingler, & 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 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 with dementia



Best practice examples

- **Caring Together: The Carer's Strategy for Scotland 2010–15** (Scottish Government).
- **Equal Partners in Care** (NHS Education for Scotland and Scottish Social Services Council).
- **Scotland's National Dementia Strategy 2013–2016**, (Scottish Government).
- **Standards of Care for Dementia in Scotland** (Scottish Government).
- **Making a Difference Campaign 2014** (Dementia Carers Voices: people at the centre) – A campaign to ensure that carers have their voices heard, and their rights and caring role recognised.
- **Charter of Rights for People with Dementia and their Carers in Scotland** (Cross Party Group on Alzheimer's).

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. The Scottish Government has initially been focusing on implementing the national dementia standards within hospital settings, including how carers are recognised and valued as partners in care. Emphasis has now been placed on Commitment 11 of Scotland's National Dementia Strategy (Scottish Government, 2013) to extend work on quality of care to other hospitals and NHS settings, and work has begun on assessing how such facilities involve and work with carers. The Triangle of Care has a very useful part to play in this process in that it can help staff gather evidence of involving carers, and ensuring carers are involved at all levels within the person with dementia's care journey.

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.

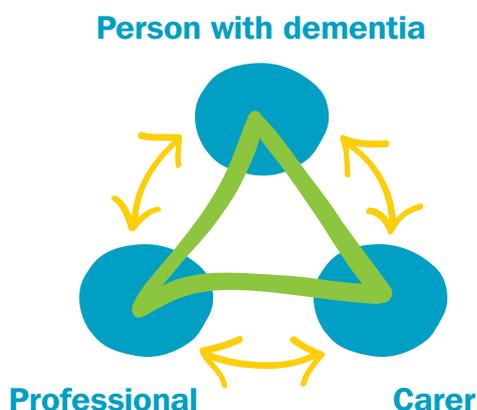


The Triangle of Care approach can be used to improve carer-staff interactions wherever they take place on the care pathway. Carers are usually willing to work with staff and do what they can to help improve the health and care needs of the person they care for.

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 the Triangle of Care 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 in this guide 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, when devising and updating care plans on impact of care and treatment offered.

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, as set out in the Promoting Excellence framework, and supported through the learning framework of Equal Partners in Care.

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:

- Dementia Champions for all wards and teams who are skilled and knowledgeable about dementia.
- Dementia link workers who provide post-diagnostic support for people with dementia and their carers.
- Alzheimer Scotland dementia nurse consultants in each NHS health board.

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.

The Standards of Care for Dementia in Scotland are clear that carers need to be recognised and valued as partners in care and be supported in their role. 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. This is important to ensure that carers feel listened to, participate in decision making and have a say in how support and treatment is provided.

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?

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 'having the potential to benefit' decision making understood and adopted which include views of carers.

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 helps care for them, 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

- **Standards of Care for Dementia in Scotland (Scottish Government).**
- **Getting to Know Me (Alzheimer Scotland, Scottish Government)** – This tool, based on earlier work carried out by NHS Lanarkshire, provides information to help staff support people with dementia.
- **Five Pillar Model of Post Diagnostic Support (Alzheimer Scotland)** – Everyone diagnosed with dementia in Scotland is entitled to one year post-diagnostic support from a named link worker (Scotland’s National Dementia Strategy 2013–2016).
- **Commitment to the Care of People with Dementia in Hospital Settings (Royal College of Nursing).**
- **Charter of Rights for People with Dementia and their Carers in Scotland (Cross Party Group on Alzheimer’s).**

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

Do all frontline staff understand “being in the carer’s shoes”?

The Promoting Excellence Framework in Scotland details the knowledge all staff should aspire to when supporting carers and people with dementia. The Equal Partners in Care framework sets out core principles essential for working with carers and young carers, and provides online training and links to relevant resources to enable staff to gain the knowledge required to better support carers. 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.

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.

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

- **Promoting Excellence Framework: A Framework for all Health and Social Services Staff Working with People with Dementia, their Families and Carers (Scottish Government).**
- **Equal Partners in Care (NHS Education for Scotland and Scottish Social Services Council)** – E-learning portal for all staff in health and social care in Scotland.
- **Best Practice in Dementia Learning Programme (University of Stirling)**
– Six part practice based study programme for all health and social care staff.

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.

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.

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 (Care and Treatment) (Scotland) Act (2003) and Adults with Incapacity (Scotland) Act (2000) 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.
- **Adults with Incapacity (Scotland) Act (2000) Code of Practice (Scottish Government).**
- **Carers and Confidentiality (Mental Welfare Commission for Scotland)** – A best practice guide for staff working with carers.

Use of power of attorney, welfare and financial guardians and advance directives, plans, or statements

It is important to establish if the person with dementia has made an advance plan, directive or statement 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 power of attorney or a particular guardianship order and in such circumstances must be consulted about future and best interest decisions if the person they are caring for 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

- **Scottish Partnership for Palliative Care** – See www.palliativecarescotland.org.uk.
- **Office of the Public Guardian (Scotland)** – See resources at www.publicguardian-scotland.gov.uk.
- **Mental Welfare Commission for Scotland** – Good practice guides and advice notes, see www.mwscot.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 coordinated, managed and led.

Alongside the Promoting Excellence skills framework (NHS Education for Scotland and Scottish Social Services Council, 2011), the University of West of Scotland, in partnership with Alzheimer Scotland, has trained around 500 Dementia Champions throughout Scotland. Dementia champions are change agents who aim to improve the experience, care, treatment and outcomes for people with dementia, their families and carers in general hospitals and at the interface between hospital and community settings. In social care settings these are known as Dementia Ambassadors and there are around 600 currently trained by Scottish Social Services Council.

The Triangle of Care supports Dementia Champions. As the roles develop and expand within acute care settings, there could be the potential for Champions to take on specific

responsibility for carers. While this is not primarily the role of Dementia Champions it would seem a good model to look at when thinking about a defined post. It is important to have someone who has a specific responsibility for liaising between ward staff, Dementia Champions and the person with dementia, their families and 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

- **Dementia Champions** – The aim of the Dementia Champions programme is to support the development of Champions as change agents in improving the experience, care, treatment and outcomes for people with dementia, their families and carers in general hospitals and at the interface between hospital and community settings (various settings throughout Scotland).

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

The Standards of Care for Dementia in Scotland are clear that carers need to feel properly supported in their role and know where to get help if needed.

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 Dementia Champion/coordinator 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 Letter of introduction (NHS Lanarkshire).

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

- Dementia Champions within hospital and community settings.

Ward orientation/carers 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 associated 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 care pathway for carers 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 allocated to one member of staff. 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

- **Coping Well with Dementia (NHS Health Scotland and Alzheimer Scotland)** – A practical book for carers.

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. Coordination between the relevant community teams or care home staff, families, 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

- **Promoting Excellence Framework: A Framework for Health and Social Care Staff Working with People with Dementia and their Carers (Scottish Government, Scottish Social Services Council, NHS Education for Scotland).**
- **Information leaflets for carers on discharge planning, managing behaviour, and dementia (various settings).**

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 board or the local authority social

services, third sector or jointly. The Standards of Care for Dementia in Scotland are clear that all service providers need to ensure that people with dementia and their carers will be able to easily obtain information and advice about support and care services that are available locally.

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/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

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 (Social Work (Scotland) Act 1968, as amended by the Community Care and Health (Scotland) Act (2002). Young carers under the age of 16 have the same rights to an assessment.

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

- **Dementia cafes (Alzheimer Scotland operated throughout Scotland)** – Provide support and information for people with dementia and their carers.
- **Carers Trust Scotland’s network of carer services** – See www.carers.org to find services.
- In Lothian, a range of support services including information and support for carers and people with dementia are on offer – See www.alzscot.org/services_and_support/search1919_edinburgh_service.
- **Scottish Young Carers Services Alliance** – Services operating throughout Scotland to support young carers, see www.carers.org to find services.
- **Standards of Care for Dementia in Scotland** – Sets out expected standards for all services (Scottish Government).

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. Regular audits against the Triangle of Care can support wider assessments of how services are performing against the Standards of Care for Dementia in Scotland.

Best practice examples

- **Standards of Care for Dementia in Scotland** – Sets out how services can use the standards to ensure the quality of dementia care and highlights importance of obtaining feedback from carers (Scottish Government).

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. It also means that their rights are recognised and protected at all levels through the care pathway.

Services for carers

In some locations, services for carers may be provided by voluntary organisations and sometimes these also manage carers support workers. All frontline staff should make themselves aware of their local carer support provision and other services.



Appendix 1: The 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 coordinated 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 allow this to be shared 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

	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	Treatments and strategies for medication management are explained to the carer.								
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	<p>The training includes:</p> <ul style="list-style-type: none"> • Understanding of carers' needs, and rights, 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	<p>Training involves the perspectives of both carers and people with dementia.</p>								

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/Guardianship powers 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.								
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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

Many of 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.

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Carers Trust Scotland

Suite 1/2
Skypark 3
14–18 Elliot Place
Glasgow G3 8EP

Tel: 0300 123 2008
Fax: 0141 204 3769
Email: scotland@carers.org

Carers Trust

32–36 Loman Street
London SE1 0EH

Tel: 0844 800 4361
Fax: 0844 800 4362
Email: info@carers.org

www.carers.org
www.youngcarersmatter.org
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