The Triangle of Care

Carers Included: A Guide to Best Practice for Dementia Care

Wales edition

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 RCN Foundation, the Triangle of Care: Carers Included: A Guide to Best Practice for Dementia Care Wales edition has been a collaborative effort between the Royal College of Nursing and Carers Trust Wales. It has been developed from the original Triangle of Care for dementia, which was 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.

This guide has been developed in recognition of the political and cultural differences people with dementia and their carers face in Wales. The focus on better supporting people with dementia has never been higher and yet opportunities for involving carers in this process remain hugely under-developed.

We hope that this document will be a useful resource to encourage and support meaningful engagement.

We would like to thank RCN Wales for supporting the development of this publication, all the contributors of best practice examples and of course carers themselves.

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Wales edition

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“The Foundation is proud to support the development of this guide in partnership with Carers Trust and the Royal College of Nursing. At a time when the numbers of people being affected by dementia is rising, this invaluable guide has never been more needed.”

**Deepa Korea,**  
Head of the RCN Foundation
Foreword

Carers Trust Wales and the Royal College of Nursing are delighted to have been able to explore an adaptation of the Triangle of Care project to meet the needs of carers of people with dementia in acute hospitals in Wales.

According to the National Assembly for Wales Research Service, dementia is the top health concern in Wales and yet Wales has the lowest rate of diagnosis across all UK nations at just 43%.¹ There are an estimated 45,000 people in Wales currently living with dementia and this figure is predicted to rise steadily over the next decade bringing with it dramatic financial and human impact. The cost to the Welsh economy is an estimated £1.4bn a year which includes costs to the NHS and social services, although research shows that people with dementia, carers and their families currently bear around two-thirds of the costs themselves (National Assembly for Wales Research Service, 2016).

In Wales, 50% of health boards have shown an active interest in implementing a Triangle of Care model and support is growing within other health boards throughout Wales. We hope the new Welsh edition 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.

About Carers Trust Wales

Carers Trust Wales is part of Carers Trust, a major 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.

With locally based Network Partners we are able to support carers in their homes through the provision of replacement care, and in the community with information, advice, emotional support, hands on practical help and access to much needed breaks. We offer specialist services for carers of people of all ages and conditions and a range of individually tailored support and group activities.

About the Royal College of Nursing

The Royal College of Nursing is the world’s largest nursing union and professional body. We represent more than 435,000 nurses, student nurses, midwives and health care assistants in the UK and internationally.

About the RCN Foundation

The RCN Foundation was set up in 2010 to support the nursing community. The charity funds individuals and organisations to undertake courses, projects and activities to make improvements and innovations in nurse led care for the benefit of their patient base and the wider public.

1. For the latest figures see: www.dementiastatistics.org/statistics/diagnoses-in-the-uk.

Simon Hatch, Director of Wales, Carers Trust and Stephanie Aiken, Deputy Director of Nursing, RCN
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.

“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.

“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
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.

Maintaining momentum but also supporting a greater level of recognition among service providers that the use of the Welsh language for example, is not just a matter of choice but also a matter of need, is vital. Many vulnerable people and their families need to access services in their first language, such as older people suffering from dementia who may lose their second language.

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 and Social Services Inspectorate Wales’ 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 Wales 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) which from April 2009, does now include the Deprivation of Liberty Safeguards. Balancing the needs and views of carers with those of the person with dementia is essential within this as the The Deprivation of Liberty Safeguards form part of the Mental Capacity Act (2005). These safeguards apply in
respect of people who lack capacity specifically to consent to treatment or care in either a hospital or care home that, in their own best interests, can only be provided in circumstances that amount to a deprivation of liberty, and where detention under the Mental Health Act 1983 is not appropriate for the person at that time.

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). It also puts into practice one of the main principles set out in the Bevan Commission as part of the Prudent Healthcare agenda which is ‘to achieve health and wellbeing with the public, patients and professionals as equal partners through co-production’. (Bevan Commission, 2015).

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 themselves and/or communicate their wishes or to revert to their first language, carers may need at times to act on their behalf (Welsh Government, 2016). 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

“Throughout my career, I’ve seen many situations where there has been a lack of availability of Welsh-medium staff which has led to a misinterpretation of patients’ needs or even a misdiagnosis because patients are confused, in pain or have lost the ability to understand and speak English.”  

Service provider

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?

“Wellingness 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

At the core of all arguments for strengthening Welsh language provision in health, social services and social care is patient safety, dignity and respect. Care and language go hand-in-hand and the quality of care can be compromised by the failure to communicate with people in their first language (Welsh Government, 2016).
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

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.

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

Best practice examples


- **This is Me** (RCN and Alzheimer’s Society). See www.alzheimers.org.uk/info/20033/publications_and_factsheets/680/this_is_me.


Best practice example

Supporting carers in hospital

Involvement of carers can be a particular issue within inpatient services. Care in General Hospitals Second Round Audit 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 January 2016, Glaslyn ward at Ysbyty Gwynedd became the first ward in Wales to formerly adopt and register their participation in John’s Campaign: for the right of a carer to stay with an individual with dementia in hospital. Glaslyn Ward has introduced a Carers Passport whereby carers of patients with dementia or delirium are issued a Carers Passport which allows them to visit the person they are caring for outside visiting times. This initiative is in the process of being rolled out to other wards throughout Betsi Cadwaladr Local Health Board. See http://johnscampaign.org.uk/#/group/betsi-cadwaladr.

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.
- Information on an ‘active offer’ with regard to what services in the Welsh language a carer and the person with dementia can expect to receive.
- 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’s 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.scie.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 Information Booklet (Betsi Cadwaladr Health Board) – Covering carers’ rights, importance of self care and information on local/national carer support services. See www.wales.nhs.uk/sitesplus/861/page/61372.

- 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

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

Best practice examples

- **Best Practice in Dementia Learning Programme** – A learning resource for all frontline health and social care staff developed by Dementia Services Development Centre, University of Stirling and accredited by Royal College of Nursing. See [http://dementia.stir.ac.uk/education/flagship-courses/best-practice-learning-programme](http://dementia.stir.ac.uk/education/flagship-courses/best-practice-learning-programme).

- **The South East Cardiff Community Resource Team, (Cardiff and the Vale Health Board)** – Developed a variety of resources including a mnemonic to remind staff of key things to remember when treating a patient with dementia, a shorter screening tool to help aid diagnoses and awareness raising tools for health and care staff. Over 95% of staff have received the dementia friends and MoCA (Montreal Cognitive Assessment) training which has increased awareness, improved assessment and increased referrals onto the Memory Team, contributing to diagnosis and appropriate support and signposting. MOCA is a rapid screening test for mild cognitive dysfunction.

- **The Butterfly Scheme** – Encourages staff to use a carer sheet as well as helping staff to understand the carer perspective. See [http://butterflyscheme.org.uk](http://butterflyscheme.org.uk).

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

Caldicott is a key element of the Information Governance agenda in Wales, providing organisations working in health and social care with a set of recommendations and principles to help ensure that a person’s identifiable information is adequately protected. In 2012 a review identified the need for a seventh principle which clarifies the value of sharing information. See The Information Governance Review To Share or Not to Share (Department of Health and Social Care, 2013).

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

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. See www.rcpsych.ac.uk/healthadvice/partnersincarecampaign/carersandconfidentiality.aspx.
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


- **Marie Curie Palliative Care Dementia Service, Hywel Dda** – Helping patients with end-stage dementia access palliative and end of life care services. See [www.ehospice.com](http://www.ehospice.com).


- **Dementia: Commitment to the Care of People with Dementia in Hospital Settings (RCN)**. See [www.rcn.org.uk/professional-development/publications/pub-004235](http://www.rcn.org.uk/professional-development/publications/pub-004235).
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

- Clinical Board Dementia Champions (Cardiff and the Vale University Health Board). See www.cardiffandvaleuhb.wales.nhs.uk/dementia-champions.

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

- Coming into Hospital: Information Leaflet for Family Carers (St Helens and Knowsley Teaching Hospital). See www.sthk.nhs.uk/patients-visitors/patient-information-leaflets/carers.

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 examples

- Initial Family Liaison Meeting (Somerset Partnership NHS Foundation Trust) – A process whereby carers are offered an initial meeting.

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.

The active offer

People with dementia often revert to their first language or have more difficulty with memory in a second language. Some will find the struggle to translate harder and some will want the comfort and reassurance of hearing a familiar language. Sadly, past experiences of people with dementia and carers receiving
health and social care services, describe situations in which very little sensitivity or respect were shown for language.

In 2016, in an attempt to address this, the More than Just Words strategy (Welsh Government, 2016) framework was introduced.

One of the key principles of More than Just Words has been the concept of the active offer. An active offer simply means a service provider offers a service in Welsh without someone having to ask for it. It means creating a change of culture that takes the responsibility away from the patient/carer (who is already in a vulnerable position) and places the responsibility on service providers.

Using first language isn’t just a choice, it’s often a clinical need. Staff should be clear what the active offer is and make sure it’s communicated as part of any carer introduction. This first means having the conversation about services you can offer in Welsh. Can you assign a Welsh speaking staff member to support a particular family? Do you have Welsh language information resources written or online? Can you turn the TV/radio to a Welsh channel? Or can you simply ensure your staff learn a few simple social Welsh phrases such as “Bore da!” or “Paned o de?”.

Knowing what you can and can’t provide in Welsh and then sharing this information with carers will offer much needed reassurance.

Best practice examples

- Dignity in Care – Welsh language toolkit – Focusing on the importance of language in maintaining dignity in care, particularly in the care of the older person and those with dementia. See http://gov.wales/topics/health/publications/socialcare/reports/dignity/?lang=en.


- Gofalu Trwy'r Gymraeg – Caring Through Welsh App – Created for Swansea University and the Coleg Cymraeg Cenedlaethol to help students and health workers feel confident when using Welsh language skills as part of their studies or in the workplace. See https://itunes.apple.com/gb/app/gofalu-trwyr-gymraeg/id668425270?mt=8.

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**

- Create your own Information Prescription through NHS Choices. See www.nhs.uk/pathways/dementia.


- Understanding Dementia – Living well with Dementia; Information for Patients and Carers (Southampton University Hospital). See www.uhs.nhs.uk/Media/ControlledDocuments/Patientinformation/Other/Living-well-with-dementia.pdf.

- Dementia Carers’ Pathways (REPoD) – Booklet developed by carers in Devon. See www.dementiapartnerships.org.uk/archive/communities/carers/dementia-carers-pathways-booklet.

**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. Ensuring carers of people with dementia are involved, from the moment of admission to hospital to the moment of discharge, is one of the actions set out in More than Just Memory.
Loss. Carers should be accepted as part of the care team who can provide insight, facilitate communication (and informed consent) and ensure continuity. Carers must have a right to remain with the person they care for and support their care unless this is clearly not in the patient’s best interests (Older People’s Commissioner for Wales, 2015). 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.

A lack of co-operation between services creates unnecessary difficulties and barriers for people living with dementia and their carers.

“You can’t split a person up into social care and health care needs. The two need to go hand in hand.”

Carer
(Older People’s Commissioner for Wales, 2015).

Best practice examples

- Information leaflets for carers on dementia, delirium and discharge planning (Nottingham University Hospital).
- CARTREF – Care Delivered with Telemedicine to support Rural Elderly and Frail Patients. See www.goodpractice.wales/casestudy-9848.

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 example**

- **Young Carers Toolkit** – A training aid for health, education, social services professionals, young carers and young adult carers. See [http://youngcarerstoolkit.co.uk](http://youngcarerstoolkit.co.uk).

- **Making the Road Less Rocky (Carers Trust)** – Information for professionals supporting carers of people with dementia. [https://professionals.carers.org/roadlessrocky](https://professionals.carers.org/roadlessrocky).

- **Dementia Support Service** – Available in all memory clinics across North Wales providing advice and support for all newly diagnosed people with dementia and their carers. See [www.nwcrossroads.org.uk/dementia-support-service](http://www.nwcrossroads.org.uk/dementia-support-service).

- **Hospital based carer support workers** – Betsi Cadwaladr and Abertawe Bro Morgannwg University Health Boards are among a growing number of health boards funding carer support officers in their acute settings as part of their discharge, multi-disciplinary or patient flow teams. See [www.wales.nhs.uk/news/42604](http://www.wales.nhs.uk/news/42604).

- **Carer’s cafe (University Hospital Southampton)** – Admiral Nurse service provides a support group for carers of people with dementia who are visiting in hospital. See [www.carersinsouthampton.co.uk/carers-cafe-at-southampton-general-hospital](http://www.carersinsouthampton.co.uk/carers-cafe-at-southampton-general-hospital).

**Carer’s assessment**

The Social Services and Well-being (Wales) Act 2014 came into force in April 2016, bringing with it significant changes for carers including new rights and duties.

The Act gives carers the same rights as those they care for, and defines a carer as: ‘A person who provides or intends to provide care for an adult or disabled child.’

The focus of the legislation is protecting the well-being of the carer and person who is cared for, defined as including:

- Physical, mental and emotional well-being.
- Protection from abuse and neglect.
- Education, training and recreation.
- Securing rights and entitlements.
• Contribution made to society.
• Social and economic well-being.
• Suitability of living accommodation.

For adults, it also includes control over day-to-day life and participation in work. For children, it includes physical, intellectual, emotional, social and behavioural development and welfare.

The Act places a duty on the local authority to provide a carer’s assessment where a carer appears to be in need of support. A carer’s assessment must include:

• The extent to which the carer is able and willing to provide the care and to continue to provide the care.
• The outcomes the carer wishes to achieve.

The local authority must involve the carer, who should feel that they are an equal partner in their relationship with professionals, and has a duty to prepare and keep under review a support plan for a carer who has been assessed as having eligible needs.

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

• National Audit for Dementia (Royal College of Psychiatrists) – Working with hospitals providing general acute inpatient services across England and Wales, to measure criteria relating to care delivery which are known to impact on people with dementia admitted to hospital. See www.rcpsych.ac.uk/workinpsychiatry/qualityimprovement/nationalclinicalaudits/dementia/nationalauditofdementia.aspx.

• 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. See www.kingstonhospital.nhs.uk/media/178149/a05673_carers_policy_-2-.pdf.

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. See www.1000livesplus.wales.nhs.uk/mh-dementia.

The Triangle of Care around the UK

Since the launch of the original Triangle of Care guide (The Princess Royal Trust for Carers, 2010), the project is now working with 90% of mental health trusts in England. 31 trusts are currently working to embed the programme in their services and with the support of NHS England we now have a resource for young and young adult carers.

In Scotland, funding from the Scottish Government is helping us implement the Triangle of Care in 12 health board areas.

In Wales, three health boards (Hywel Dda, Betsi Cadwaladr and Abertawe Bro Morgannwg University), have shown an active interest in implementing a Triangle of Care model. A further two are seeking advice about how they can influence the adoption of the Triangle of Care in their own local health board regions. Funding is being sought to help develop an infrastructure to support this work further across Wales.

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 care support workers. All front line staff should make themselves aware of their local carer support provision and other services. Find Carers Trust services near you on Carers.org.
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**

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<thead>
<tr>
<th>Criteria</th>
<th>R</th>
<th>A</th>
<th>G</th>
<th>Where are we now?</th>
<th>Action plan</th>
<th>Evidence of achievement</th>
<th>By whom?</th>
<th>By when?</th>
</tr>
</thead>
<tbody>
<tr>
<td>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).</td>
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<td>1.2 The person with dementia is consulted about involvement of the carer, unless this is not possible.</td>
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<td>1.3 The main carer or carers are routinely identified and their views sought within the assessment process to help inform care.</td>
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<td>1.4 An assessment of carer needs is carried out.</td>
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<td>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.</td>
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<td>1.6 A record is made of lasting power of attorney(ies) and whether an advance plan and/or directive is in place.</td>
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<td>1.7 People with dementia and their carers are regularly updated and involved with care plans and treatment which focus on all their needs.</td>
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<td>1.8</td>
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<td>Advice about advocacy, information and support services are made available to both the carer and the person with dementia.</td>
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### Standard 2 – Staff are carer aware and trained in carer engagement strategies

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<td>2.1</td>
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<td>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.</td>
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<td>The training includes:</td>
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<tr>
<td>• Understanding of carers’ needs and how these relate to the person with dementia.</td>
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<td>• Carer expectations about assessment, treatment and support.</td>
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<td>• Dealing with carer queries and concerns.</td>
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<td>• Advising on sources of help and support.</td>
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<td>• Advising on treatments, approaches to care and managing medicines.</td>
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<td>• How to involve carers and people with dementia in the delivery of care, including at the end of life.</td>
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<td>• Balancing differing needs of people with dementia and their carers.</td>
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<td>Training involves the perspectives of both carers and people with dementia.</td>
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</table>
### Standard 3 – Policy and practice protocols regarding confidentiality and sharing information, are in place

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

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Where are we now?</th>
<th>Action plan</th>
<th>Evidence of achievement</th>
<th>By whom?</th>
<th>By when?</th>
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</thead>
<tbody>
<tr>
<td>4.1 Ward sister or manager is responsible for ensuring carer involvement by all staff.</td>
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<td>4.2 Carer leads/champions are in place and have an understanding of dementia.</td>
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<tr>
<td>4.3 Carer leads/champions work closely with local dementia champions to provide support for carers.</td>
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</table>
**Standard 5 – A carer introduction to the service and staff is available, with a relevant range of information across the acute care pathway**

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<tr>
<th>Criteria</th>
<th>R</th>
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<tbody>
<tr>
<td>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.</td>
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<td>5.2 An information pack, which explains practical matters, how to get involved, carer support, information about discharge and support services, is made available.</td>
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<tr>
<td>5.3 Policies and procedures about carer involvement and information about carer support are made readily available and clearly advertised.</td>
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<td>5.4 Meeting and greeting protocols are in place for carers to offer support, reduce distress and address concerns.</td>
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<tr>
<td>5.5</td>
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<tr>
<td>Carers are offered an early appointment to hear their story, share information about the person they care for and address concerns.</td>
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<td>5.6</td>
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<td>The cultural and language needs of carers has been addressed in the preparation of the information pack.</td>
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<td>5.7</td>
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<td>The format of the information pack is flexible and regularly updated.</td>
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<td>A member of ward or team is made responsible for commissioning, storing and issuing the packs.</td>
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<td>Staff offer carers the opportunity to have a conversation and encourage them to access support.</td>
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<td>5.10</td>
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<td>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.</td>
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<tbody>
<tr>
<td>5.11 The carer is asked for feedback regarding the service provided as part of service monitoring and improvement.</td>
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<td>5.12 Staff have considered how best they can meet the needs of a person with dementia through the Welsh language and have made an active offer to the person/carers.</td>
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### Standard 6 – A range of carer support is available

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<th>Evidence of achievement</th>
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<th>By when?</th>
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<tbody>
<tr>
<td>6.1 Dedicated peer and carer support services are available locally.</td>
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<tr>
<td>6.2 Local advocacy services are available for carers and people with dementia.</td>
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<th>Evidence of achievement</th>
<th>By whom?</th>
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<tbody>
<tr>
<td>6.3</td>
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<td>Carer has access to one-to-one support when needed.</td>
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<td>6.4</td>
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<td></td>
<td>Need for support on discharge is discussed with the carer and the person with dementia.</td>
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<td>6.5</td>
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<td></td>
<td>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.</td>
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<td>6.6</td>
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<td></td>
<td>A referral is made to local services for carer support where required.</td>
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</table>
References


Older People’s Commissioner for Wales (2015), *More than Just Memory Loss: The Experiences of People Living with Dementia and Those Who Care for Them* (Older People’s Commissioner for Wales). See: [wwwOLDERPEOPLEWALES.COM/EN/PUBLICATIONS/PUB-STORY/16-03-14/DEMENTIA_MORE_THAN_JUST_MEMORY_LOSS.ASPX#.WhLNG7p2ty0](http://wwwOLDERPEOPLEWALES.COM/EN/PUBLICATIONS/PUB-STORY/16-03-14/DEMENTIA_MORE_THAN_JUST_MEMORY_LOSS.ASPX#.WhLNG7p2ty0).

Royal College of Nursing (2013), *Dementia: Commitment to the Care of People with Dementia in Hospital Settings* (Royal College of Nursing). See: [www.rcn.org.uk/professional-development/publications/pub-004235](http://www.rcn.org.uk/professional-development/publications/pub-004235).


Royal College of Nursing (2011), *Dignity in Dementia; Transforming General Hospital Care Project*.

Social Services and Well-being (Wales) Act 2014.


### Additional resources

**Alzheimers’ Society Cymru**
www.alzheimers.org.uk/homepage/316/wales_cymru

**Carers Trust Wales**

**Dementia Partnerships**
www.dementiapartnerships.org.uk

**Dying Matters**

**Information Governance and Caldicott**
www.wales.nhs.uk/sites3/home.cfm?orgid=950

**Royal College of Nursing**
Dementia. See: [www.rcn.org.uk/clinical-topics/dementia](http://www.rcn.org.uk/clinical-topics/dementia).
Dementia: Our Work. See: [www.rcn.org.uk/clinical-topics/dementia/current-work](http://www.rcn.org.uk/clinical-topics/dementia/current-work)

**Royal College of Nursing Wales**
www.rcn.org.uk/wales

**Royal College of Psychiatrists**
www.rcpsych.ac.uk/healthadvice/problemsdisorders/dementiaandmemoryproblems.aspx

**Tide (Together in Dementia Everyday)**
http://tide.uk.net/carers

**Welsh Government**