# CARER’S POLICY AND GUIDELINES

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<thead>
<tr>
<th>Post holder responsible for Policy:</th>
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<tr>
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**This policy etc. covers:**

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**Other (Please specify):**

- Note: This policy has been assessed for any equality, diversity or human rights implications.

**Controlled document**

This document has been created following the Royal Devon and Exeter NHS Foundation Trust Policies, Procedures, Protocols, Guidelines and Standards Policy. It should not be altered in any way without the express permission of the author or their representative.
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### 1. Introduction
This document introduces the Royal Devon and Exeter NHS Foundation Trust’s approach to addressing the needs of carers. It includes a policy statement on the importance of addressing the needs of carers, defines what a carer is and offers guidelines for staff on how to actively engage carers, recognising and supporting them in line with national and local carer strategy and policy, together with National Service Frameworks, Valuing People and Essence of Care.

There are 73,000 carers in Devon which equates to 10% of the population. Of these approximately 10% are young people. Carers play a role that is vital, but often unnoticed and unappreciated. Carers frequently observe that their caring responsibilities tax their own health and well-being. Comparatively minor but coordinated changes to the Trust’s response to carers and their need for recognition and support would enable the organisation to deliver excellent services that also accommodate carers. Not only would carers benefit from the Trust adopting a proactive approach, but the Trust could also expect that better communication and structured interaction with carers would result in better outcomes for both patients and their carers.

2. Legal Framework

The Government’s agenda is to provide support to people in their own homes and it has charged health and local authorities to reduce residential and nursing home placement.

The Trust has a statutory duty to involve and consult patients, carers and their families in service planning and delivery, as per Section 242 of the NHS Act 2006, Public involvement and consultation.

Carers have had the right to recognition since the Carers (Services and Recognition) Act was passed in 1995. They have also had the right to be consulted about their willingness and / or ability to provide or continue to provide care for another person. They have had the right to have a Carer’s Assessment in their own right since the Carers and Disabled Children’s Act 2000.

The Carers (Equal Opportunities) Act 2004, affecting carers in England and Wales, places a duty on NHS bodies and local authorities to promote the health and welfare of carers and to inform them of their right to an assessment.

Ensuring that all service providers within the Trust respect these rights through the implementation of the policy and guidelines would contribute towards equity for all carers, whether they are themselves patients or are the carers of patients.

Awareness of current legislation can aid the professional when arranging a cared for patient’s discharge / transfer especially when discharging the patient home. Discovering and documenting whether a patient has a carer willing to continue or to take on new or greater responsibilities’ gives the professional a greater understanding of the patient’s situation.

3. Policy Statement
The Royal Devon and Exeter NHS Foundation Trust recognises that carers play an important role in the continuing care of many of its patients following discharge, effectively picking up patients’ health and other care needs in the community. By implementing best practice, the Trust wishes to promote the health and independence of carers. It will achieve this by

- identifying and recognising carers of all ages
- ensuring carers are aware that they have certain rights, including the right to a carer’s assessment
- allowing them to make choices about their caring role
- actively seeking patients’ permission to share information with carers
- involving carers in patients’ discharge planning
- offering relevant support
- monitoring their experience and satisfaction through surveys and carer organisation feedback
- identifying and supporting patients with a caring responsibility
- keeping carers informed of patient condition

Carers who are patients themselves may have a special need for both a longer convalescence and more respite care for the person they look after. They may need additional support on discharge, as well as to be directed to sources of support.

It is envisaged that the Trust will also benefit from the improved communication, involvement and appropriate support offered to carers; benefits such as fewer delayed discharges, fewer carer-generated complaints and better customer relations with users and carers. Better informed and supported carers are also less likely to break down under the strain of caring, something which can lead to the emergency readmission of patients, sometimes with their carers.

4. Definition of a carer

A carer is someone who, by looking after a frail, ill or disabled partner, relative, friend or neighbour, enables them to stay at home, or to return to it. Without the carer’s care, the cared-for person might remain longer in hospital than necessary, or be in intermediate or transitional care, or in a residential or nursing home. These beds and places are in short supply; carers are providing a service that frees the healthcare professionals to care for those who need acute care or specific rehabilitation.

- These carers are not paid, although some are eligible for benefits payments.
- Carers come in all ages, and both genders.
- At least one third of carers are 60 or older; many others care for an older person.
- Carers who are themselves patients may have special needs which will have to be taken into consideration.
- Carers have rights, including the right to refuse to take on or continue the responsibility of caring for someone and the right to an independent assessment of their caring role; these are legal rights.
• Carers also have needs for information about the condition of the patient, i.e. should deterioration occur or post discharge information and training which will support them in their caring role.

4.1 Young Carers

The Children Act 2004 needs to be considered at all times.

A significant number of carers are children or young people.

• A young carer is a child or young person whose life is affected by caring for someone with a physical or learning disability, or who has mental health problems, over and above “just helping out”.

• Young carers have caring responsibilities that would normally be expected only of an adult.

• The person they care for will usually be a parent, a brother or sister, or a grandparent.

• A young carer may be caring for parents who misuse drugs and alcohol.

• Many young carers, but certainly not all, are living within one-parent families and can be either a primary or secondary carer, providing a range of care from basic, necessary domestic duties to very intimate care.

• Most young carers say that they are happy to continue their caring roles, but they do need recognition and support for what they are doing.

• No health care/community care package should rely on the caring role of a young person under the age of 18. All services have a role to play in identifying young carers and ensuring that they are supported and able to make informed choices about the level of caring responsibility that they take on.

• Trust staff encountering young carers need to be aware that there is a range of services for young carers in Devon. All referrals should be made to a young carer’s worker at The Westbank (see contacts, section 8). This can be a stressful time for your carers. They will need reassurance that the actions taken by health professionals are in the best interests of the whole family.

• In collaboration with carers reassurance is to be provided that any issues will be resolved in the best interest of the whole family.

4.2 Parents as Carers

Parents are sometimes also their child’s carers, in the sense that the child may have special needs and require more care or specific treatments from his or her parents or guardians. In all cases, parental responsibility must be established before proceeding.
The Children Act 2004 needs to be considered at all times.

Good communication between Trust staff and parents (or guardians) who are their child’s carers is essential, as is good documentation.

- Find out if the parents’ caring responsibilities are new or well established and document the data; new carers will almost certainly have quite different concerns and needs compared to those of established carers.

- Staff may need to learn from parents who are experts in their child’s care management.

- Parents who are also their child’s carers need to have their additional role recognised by Trust staff.

- Staff should be proactive about offering parents as carer’s information and support.

- Support may take the form of offering training to a parent or guardian who is also a child’s carer.

- Any training in a technique which will make it easier for the parents as carers to look after their child at home must be carried out by qualified staff following clear teaching plans based on best practice.

- The disclosure of a young child’s personal health information including a realistic assessment of his or her continuing care needs to his or her parents who are also the carers is normally straightforward.

- Personal health information concerning a child under the age of 16 can be given to his or her parents or legal guardians, subject to the child’s agreement and his or her being assessed against the Fraser guidelines / being Gillick competent.

- With older children who have the capacity to comment on their treatment and care management, the situation can be more complex, and may have to take into account a child’s own need for privacy and autonomy.

- Parents, as carers of their child, need information about their child’s care requirements to successfully plan managing their caring responsibilities at home.

- Well-informed staff and good communication between the various parties can normally resolve any conflict between the needs of the young person and those of his or her carers.

- In cases of young adults with learning disabilities, the carers still need information even though every effort should be made to involve the patients in decisions about their discharge and care needs at home, as well as the disclosure of personal health information to their parents. The Trusts Learning Disability Liaison Nurse can be contacted for further advice and support.
• Check that parents are also the patient’s guardians if the young adult has limited capacity to make decisions. This is required to ensure that the parent or guardian has legal responsibility for the ‘cared for’ young person.

• The guardians of an adult with learning disabilities will need information about the patient’s health, including his or her continuing care needs after discharge.

• Where families are divided, staff may need to take specialist advice about how to handle the needs of perhaps two parents who share or intend to share responsibility for their child’s care, yet live apart.

4.3 Carers of people with learning disabilities

• The Trusts Learning Disability Liaison Nurse can be contacted to answer any questions or offer support.


• “Family and other carers should be involved as a matter of course as partners in the provision of treatment and care, unless good reason is given and Trust Boards should ensure that reasonable adjustments are made to enable and support carers to do this effectively. This will include the provision of information, but may also involve practical support and service coordination”. *Healthcare for All (July 2008).*

5. Addressing Carers Needs

The Trust considers that there are *nine stages* to addressing carers’ needs:

5.1 Identification of carers

1. Carers frequently fail to think of themselves as such, regarding themselves as partners, parents, relatives, friends or neighbours. Good communication skills will be needed by staff to elicit this information positively. *Routine use of the Clinical Integrated Documentation for all patients will assist staff to achieve this as the questions are scripted.*

2. Carers need to be identified as early as possible, using the Clinical Integrated Documentation (CID). In the case of elective procedures, it may not yet be possible to obtain this information from the referring GP. Carer identification is part of pre-admission procedures and documentation and will help to identify discharge issues.

3. A patient’s carer status during his or her stay in hospital should be reviewed. Often a partner, relative or friend will accept responsibility for the post-discharge care needs of a patient who was independent before his or her current illness. Sometimes an existing carer may refuse to take on greater responsibilities or continue the caring role. Any changes need to be documented and factored in to the patient’s discharge plan. Refer to Trusts Complex Discharge policy.

4. Carer details must be recorded clearly using the appropriate forms within the Clinical Integrated Documentation (CID), kept with the patients’ notes or nursing records and referred to by all members of the multidisciplinary team.
5. Ideally the patient should identify their carer to staff, but the patient will still need to be asked if he or she wants the nominated carer to continue in that role. A refusal should not always be taken at face value and on occasions may need to be investigated further for any suspicious circumstances as part of the Trusts commitment to safe guarding vulnerable adults. The Safeguarding Vulnerable Lead can be contacted for advice (see Appendix)

6. If the patient is too unwell to give any information, staff should try to discover from the patient’s visitors if there is a carer and then contact him or her as soon as possible.

7. The patient’s consent (or otherwise) regarding the disclosure of personal information about his/her diagnosis, treatment and care needs to the carer must be recorded in the Clinical Integrated Documentation (CID).

8. Staff should ask the carer for confirmation that he or she is willing and able to take on or continue looking after the patient following discharge home. This should be asked in private, as patients sometimes nominate a person as their carer without any prior discussion with the proposed carer.

9. The patient-carer relationship is confirmed and documented in the Clinical Integrated documentation.

5.2 Information for healthcare staff on consent to disclose information:

- If the patient is lack capacity or is incapable of making a decision, the Trust has a duty to act in that patient’s best interest. A best interest check list is available on the Trusts intranet site. The Trusts Safeguarding Adults process should be followed.

- If, in the multidisciplinary team’s opinion, the patient’s best interests are served by disclosing personal information to a carer to provide care, or to enable the carer to assess whether he or she is able to provide the required care, then that disclosure may be made and the decision recorded in the patient’s records within the “Mental Capacity Assessment Form”.

- The decision as to whether a person is mentally competent or has the capacity to give consent for the disclosure of his or her personal information to the carer can be made by a member of the multidisciplinary team so long as they document any decisions made in the “Mental Capacity Assessment form”. Form available on Trust intranet titled Adults who are unable to consent to investigation or treatment.

- Deciding if a person has the mental competence or capacity to make this decision is a legal decision: it has legal implications.

- There are many shades of capacity to make decisions, e.g. a person may have the capacity to make a will, but not be able to manage his or her financial affairs.

- A member of the multidisciplinary team would need to assess the patient’s competence or capacity for each decision to be made.

- If a patient has a severe impairment of capacity and would not be able to give consent, then it would be meaningless and wrong to ask him or her the question.
• A carer would be able to refuse to take on any or greater caring responsibilities post-discharge unless this information is disclosed to him or her before the patient’s discharge.

For more information and guidance on the issue of consent, please refer to the Trust’s Policy Document for the Consent to Examination, Investigation or Treatment

5.3 Process for disclosing information to the carer:

Subject to the conditions in 5.2:

1. Offer carers information about:
   • the medical condition of the patient
   • what the patient’s continuing care needs are likely to be
   • what training might be available to the carer
   • a discharge plan – verbal and written
   • how to get help in looking after someone via a Carer’s Assessment

2. Explain to carers about:
   • a carer’s right to a Carer’s Assessment
   • a carer’s right to recognition and support
   • a carer’s right to refuse to take on the responsibility of caring for the patient after discharge
   • their right to access to signers/interpreters/signers or interpreters if required
   • sources of support, such as carer organisations or self-help groups
   • how to challenge decisions and access PALS or make a complaint
   • Carers right of confidentiality
   • the importance of both positive and negative feedback

3. Refer patients to Devon Carers Link (see contacts, section 8) for information about:
   • the financial implications of caring
   • services – those that are free, and those with charges
   • services available through Adult and Community Services (via Care Direct)
   • support available to carers

5.4 Offering choices to carers:

Allow carers time to make choices about:

   • taking on the role and responsibilities of carer
   • whether to continue caring
   • what level of responsibility to accept, recognising individual boundaries and constraints

5.5 Offering carers an assessment:

   • Inform carers about their right to a Carer’s Assessment, an assessment of their needs in relation to their caring role and carried out by a member of Adult and Community Services staff via Care Direct.
• Ensure that carers are offered information about how a carer’s assessment may support them; refer them to the green “Carers Link” leaflet available from the Health Information Centre.
• Promote the involvement of carers in any assessments carried out by occupational therapists, physiotherapists, community nurses etc

5.6 Supporting and Involving Carers providing care in hospital:

Manual Handling:
Many carers move and transfer the ‘cared for’ safely and effectively whilst at home. They may wish to continue this activity during the hospital stay but are under no obligation to do so. The level of involvement in movement / transfer should be instigated and guided by the carer with permission of the cared for. The Registered Nurse has the duty and obligation to ensure manual handling best practice is maintained for staff, carer and cared for. The carer can only be involved in the movement / transfer of the ‘cared for’ once they have been assessed as capable by nursing staff and only with consent from the ‘cared for’.

Medication:
Many carers administer drugs to the ‘cared for’ safely and effectively whilst at home. They may wish to continue this activity during hospital stay but are under no obligation to do so. The level of involvement in drug administration should be instigated and guided by the carer with permission of the cared for. The Registered Nurse has the duty and obligation to administer medications to patients and can only involve carers in assisting with drug administration once they have been assessed by a Registered Nurse as capable and if the cared for and the carer consent.

Personal Hygiene:
Many carers assist with personal hygiene activities for the ‘cared for’ safely and effectively whilst at home. They may wish to continue this activity during the hospital stay but are under no obligation to do so. The level of involvement in hygiene care should be instigated and guided by the carer with permission of the cared for. The Registered Nurse has the duty and obligation to ensure the patients hygiene needs are met. The carer can only be provide assistance with hygiene activity once they have been assessed as capable by nursing staff and only with consent from the ‘cared for’.

Eating and Drinking:
Many carers assist with eating and drinking activities for the ‘cared for’ safely and effectively whilst at home. They may wish to continue this activity during the hospital stay but are under no obligation to do so. The level of involvement in eating and drinking assistance should be instigated and guided by the carer with permission of the cared for. The Registered Nurse has the duty and obligation to ensure the patient nutritional needs are met. The carer can only assist with eating and drinking activity once they have been assessed as capable by nursing staff and only with consent from the ‘cared for’.

Infection control:
In terms of protection for the carer, the cared for and other patients in the hospital environment, the following points should be adhered to at all times in line with the Trusts Infection Control policy:
• Although the carer may well be providing similar care at home, the vulnerability of
  the patient to infection may be much greater whilst they are ill in hospital i.e. they
  may have IV devices, catheters, wounds etc and antibiotics that would not be
  normal for them. Therefore staff should ensure carers’ are aware of the correct
  procedures regarding hand hygiene, use of protective clothing, waste disposal and
  laundry segregation, whilst emphasizing that most of the precautions required in
  hospital will not be necessary in the home situation.

• Ward staff should clarify that the carer must not provide care to any other patients.
  Particularly at meal times when carers may feel obliged to help other patients open
  sandwiches and drinks etc which could result in cross infection if they do not think
  about hand hygiene etc when moving from their relative to others.

• Carers should not be given access to staff only areas of the ward, in particular the
  ward kitchen as this would breach food hygiene regulations, but also the clean and
  dirty utility.

• In line with the advise given to all hospital visitors, carers should be asked to stay
  away when they are unwell themselves particularly when they have diarrhoea
  and/or vomiting, flu like symptoms, coughs, colds, sore throats or other potentially
  infectious conditions.

5.7 Discharge planning

As well as providing general information about the hospital’s services and local carer
organisations, carers will need information specific to the patient in order to assess if he or
she will be able to meet the patient’s care needs at home.

1. Identify carers as soon as possible – see 5.1 above

1. See “Complex Discharge Policy” available on Trusts intranet site

2. Ensure that carers are involved (rather than just informed) at all stages of the patient’s
   journey. This would include:
   • making the decision to discharge the patient
   • discussing and agreeing practical alterations and preparations for the discharge at
     home. Carers may need time to make different working arrangements
   • agreeing the estimated date of discharge and informing the carer if this changes
   • giving the carer sufficient notice of the patient’s discharge

3. View carers as partners in the provision of healthcare by:
   • respecting and listening to their views – longer-term carers are likely to have
     valuable expertise and be skilled in caring for the patient
   • ensuring that they have the relevant information needed to plan effectively for their
     caring role - see 5.2 above.

4. Acknowledge carers’ own needs, considering:
   • the circumstances leading to their taking on the caring role
   • commitments to other family members
   • work commitments
   • cultural differences
• communication needs
• religious background
• gender
• relationship
• sexual orientation
• ethnicity
• ability
• frailty
• disability
• where they live – access / services / housing

NB: Please be careful not to make any assumptions, especially those often based on the carer’s gender, or the relationship between patient and carer. Also, even if the carer is or has been a healthcare professional, do not assume that they will be able or willing to cope with any and all caring responsibilities.

5.8 Providing support for carers

• Staff will need to be aware of sources of support for carers including local carer organisations and other community services able to provide information and support in many forms to carer (see contacts, sections 8).

• Staff will provide some information and support themselves, which may include nursing techniques. Information such as manual handling can be obtained through specially run courses for carers, run by St Johns Ambulance (see contacts, section 8)

• Staff will also need to be aware of how carers as well as patients can access the Patient Advice and Liaison Service (PAL’s) in the event of their having a concern or complaint about the service

• Information relating to “NHS Continuing Care Funding” can be located in the Health Information Centre. For other contacts please see section 8 of this policy.

• When a carer is identified please direct them to the green “Carers Link” leaflet available from the Health Information Centre.

• Referrals can be made to Adult and Community Services via Care Direct (see contacts, section 8)

5.9 Training

• Carers
Formal training for carers is not provided by the Trust but guidance on ‘helping with activities’ should be provided as necessary. St Johns Ambulance (see section 8 - Contacts) offers courses on first aid and manual handling.
• **Staff**

There is no formal training for staff on how to support carers although adhoc sessions may be arranged. Staff should refer to the Involving People section of the intranet for up to date information on carers.

### 6. Monitoring and evaluating carers experiences

Evaluation of carers’ views and experiences will be made against the standards set out above. The following ongoing methods are used to obtain feedback relating to carers:

- Patient advice and Liaison Services (PAL’s) / complaints
- Interventions at ward level
- Annual patient survey
- Monitoring of referrals made via ref 6 carried out by local carers’ organisations.
- Internal surveys

### 7. Staff who are also carers

Policy affecting staff who are also carers is stated in *Improving Working Lives*, but when such staff use Trust services as patients or carers, The RD&E Carers Policy applies.

### 8. Contacts

**The Westbank**

- **Ph:** 01392 824752
- **Fax:** 01392 823 987
- **Web:** [www.westbank.org.uk](http://www.westbank.org.uk)

Westbank provides care and promotes health to communities across Devon. At the Healthy Living Centre, people of all ages can enjoy a wealth of activities to keep body and mind healthy. This bright, modern building has purpose-built facilities including a fitness suite, cyber-cafe and Kidszone. The Community Care Centre offers care and support to more dependent members of the community through a range of services.

**Care Direct**

- **Ph:** 0845 1551007
- **SMS:** 07773 333231
- **Minicom:** 0845 1551020
- **Staff only:** 01392 381206
- **Out of hours:** 0845 600 0388
- **Web:** [www.devon.gov.uk/caredirect.htm](http://www.devon.gov.uk/caredirect.htm)

Care Direct work in partnership with Devon Social Services offering information and help for older people, vulnerable adults and their carers.

**Devon Carers Link**

- **Ph:** 0845 6431341
- **Web:** [www.devoncarerslink.org.uk](http://www.devoncarerslink.org.uk)

**Carers UK Support Line**

- **Ph:** 0808 8010878
Age Concern Devon offers a wide range of services to older people across the county including advocacy, domestic home help, enabling, information and advice, insurance, financial, legal and medical services.

Living Options Devon is a user-led organisation which exists to ensure people with physical and/or sensory disabilities and Deaf people with sign language can make an active and equal contribution in society.

St Johns Ambulance Devon offer training courses in First Aid and Moving and Handling which could benefit Carers.

9. Related documents / references

- **Carers and Disabled Children’s Act 2000**: carers have the right to a Carer’s Assessment in their own right

- **Carers at the heart of 21st Century Families and Communities: A National Strategy for Carers June 2008**

- **Carers Equal Opportunities Act 2004**


- **Healthcare for all (July 2008)**: Report of the independent enquiry into access to healthcare for people with learning disabilities.

- **Improving Working Lives, July 2000**

- **Mental Capacity Act 2005**

- **Modernising Health and Social Services: National Priorities Guidance 1999/00 – 2001/02. Shared Lead Priorities: Promoting Independence, Sept 1998**: Objective 3 states” Provide carers with the support and services to maintain their health, and with the information they need on the health status and medication of the person they are
caring for (subject to that person’s consent). As a first step ensure that systems are in place in primary care and in Social Services Authorities to identify patients and service users who are or who have carers.”

- **National Service Framework for Mental Health, 2000**: Standard Six: Caring about Carers: “All individuals who provide regular and substantial care for a person on CPA should have an assessment of their caring, physical and mental health needs, repeated on at least an annual basis, and have their own written care plan, which is given to them and implemented in discussion with them.

- **National Service Framework for Older People, 2001**: Chapter One, section 28 states that “carers’ needs should be considered as an integral part of the way in which services are provided for older people”. All eight standards recognise carers.

- **NHSE: Clinical Governance; Quality in the New NHS, March 1999** states that NHS organisations have a new statutory duty of assuring the quality of clinical care. The NSFs and NICE guidelines should be implemented as part of clinical governance.

- **Section 242 of the NHS Act 2006, Duty to involve patients**


- **The Data Protection Act 1998**

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Written by the Royal Devon and Exeter NHS Foundation Trust in consultation with Devon Carers Link and Carers UK.

July 2009
Appendix 1 – Carers Policy

IS THE PATIENT A CARER OR CARED FOR?

YES CARER

Obtain consent to share information (see C.I.D.)

Is the carer: Spouse / Partner / Friend / Neighbour

Do they receive help from Social Services?

No

Yes

Does the carer have additional support needs/ need carers assessment?

No

Devon Carers Link Leaflet (stock available from Health Information Centre)

Yes

YES CARED FOR

Obtain consent to share information (see C.I.D.)

Check who is their carer?

If carer is present agree their involvement in care plan

Discharge planning

Does the carer have additional support needs/ need carers assessment?

Yes

No

Phone Care Direct Plus to update and plan discharge 01392 381206

Social Services

Are they aware of admission?

Yes

No

Devon Carers Link leaflet is offered (stock available from Health Information Centre)

NB A carer is a person of any age who provides regular help on an unpaid basis to a person of any age who is a relative, friend or neighbour.