

Connecting you ...when it matters the most

Information for people with palliative care needs



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Introduction

This booklet has been produced to provide information to patients and carers about services and groups which may be a useful source of assistance and support. The booklet is not intended to replace conversations with and advice from health and social care professionals as circumstances will vary from person to person, but to act as a signposting tool. Other providers may be available in the local area in addition to those detailed in the booklet.

We are not responsible for and cannot guarantee the accuracy of, the contents of any websites to which we provide a link and do not necessarily endorse the views expressed within them.

If you do not have online access, please speak to the person who has given you the booklet.

Definitions

Palliative Care

Palliative care is the holistic care of patients with advanced, progressive, incurable illness, focused on the management of a patient's pain and other distressing symptoms and the provision of psychological, social and spiritual support to patients and their family. Palliative care is not dependent on diagnosis or prognosis, and can be provided at any stage of a patient's illness, not only in the last few days of life. The objective is to support patients to live as well as possible until they die and to die with dignity (General Medical Council 2010).

End-of-Life Care

People are approaching the *end of life* when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days).

(General Medical Council, Treatment and care towards the end of life: good practice in decision making, 2010)



Health Services

Health Care Roles

A variety of healthcare professionals may be involved in your care. This link explains more about some of the roles of these professionals (these services are not necessarily restricted to those with a diagnosis of cancer).

Macmillan Cancer Support:
<http://tinyurl.com/ku2e3oh>

GP, Community and Hospital Health Services

The links below provide information on local GP practices, community health services and hospital services that may be involved in your care. Healthcare professionals in your local hospital or your GP can refer you to the appropriate community service.

GP

Telephone your own GP practice to be directed to GP Out-of-Hours Services.

Chester City

<http://www.westcheshireccg.nhs.uk/whoweare/ourlocalities/chestercity.html>

Ellesmere Port and Neston

<http://www.westcheshireccg.nhs.uk/whoweare/ourlocalities/ellesmereneston.html>

Rural

<http://www.westcheshireccg.nhs.uk/whoweare/ourlocalities/cheshirerural.html>

GP Out-of-hours

<http://www.cwp.nhs.uk/services/403-out-of-hours-service>

Community Health Services

District Nurses

<http://www.cwp.nhs.uk/services/399-district-nursing>

Community Matrons

<http://www.cwp.nhs.uk/services/385-community-matrons>

Community Palliative Care Service

Chester, Ellesmere Port and Neston and Rural areas

<http://www.cwp.nhs.uk/services/402-community-palliative-care-team-including-macmillan-nurses>

Hospital Services

Palliative Care

<http://www.coch.nhs.uk>

Under 'A-Z of Services', use the drop-down menu to select 'Palliative Care'.

Other services

Continence Advisory Service

<http://www.cwp.nhs.uk/services/388-continence-advisory-service>

Dietician

This service can be accessed by your GP.

Chiropodist/podiatry

<http://www.cwp.nhs.uk/services/405-podiatry>

Mental health support and counselling

<http://www.cwp.nhs.uk/services/199-community-mental-health-teams>

Talking to your healthcare professional

It is important that you get the best out your time with healthcare professionals involved in your care and that you feel you can ask questions as stated in the NHS Constitution:

- Your healthcare professional should...
 - ... introduce themselves, be polite and listen to you.
 - ... ask your permission to carry out an examination on you.
 - ... explain any treatment they think is best for you and explain any risks of the treatment and any risks associated with not taking a treatment. They should also explain any alternative treatments.
 - ... allow you to ask questions.
 - ... give you information on what treatments and drugs are available to you.
- The decision on which treatment is best for you is a joint decision between you and your healthcare professional.
- If you decide you do not want any treatment, this should be respected and other options and choices if available should be discussed with you.

Social Care

Care in Your Own Home

This can include personal care such as assistance getting dressed or having a wash or assistance with other tasks

www.cheshirewestandchester.gov.uk

and search for 'care in your own home' or <http://tinyurl.com/pcsfbor>

Occupational Therapy

Occupational therapy can help you to maintain the skills for daily living.

www.cheshirewestandchester.gov.uk

and search for 'occupational therapy services' or <http://tinyurl.com/lu5yaxb>

Medication and Prescriptions

Speak to your GP surgery about how to access prescriptions.

Controlled Drugs

Some of the medication you have been prescribed may be classed as controlled drugs. These are drugs such as Morphine and Fentanyl which have been given to you to control pain. Unfortunately these drugs are the subject of abuse when taken without medical reason and are valuable to people who abuse drugs. Surgeries and Pharmacies have a duty to ensure that these drugs don't fall into the wrong hands. They are therefore required to ensure that it is the patient or the patient's representative collecting them. It is important to have a conversation with the surgery and the pharmacy if a representative is collecting them on your behalf to ensure the script/ medication will be given to them and that they have any necessary identification with them.

Usually this doesn't cause a problem as the pharmacy and the surgery will already be aware of the situation but it can be an issue on the rare occasion where a neighbour or friend is collecting them from a Pharmacy where the patient is not known.

If you would like further information on your medication your GP, district nurse or pharmacist will be able to help.

Patient information leaflets will be provided with your medication and may answer some of your questions.

Your district nurse, community palliative care nurse or GP will be able to advise you of the pharmacies likely to stock this medication. Some information leaflets on medicines and drugs can found at:

<http://www.patient.co.uk/medicine>



Pharmacies

Find your local community pharmacies and opening hours: www.nhs.uk search for 'looking for a pharmacy' and enter your postcode.

Condition-specific Services

Cancer

Macmillan Support and Information Centre, Countess of Chester Hospital
cancer.support@nhs.net • 01244 364 948

Chronic Obstructive Pulmonary Disease (COPD)*

www.cwp.nhs.uk
and search for 'COPD Specialist Nurses'

Heart Failure*

www.cwp.nhs.uk
and search for 'Heart Failure Service'

Neurological conditions*

Neuromuscular Centre

www.nmcentre.com

The Neuro Therapy Centre

www.neurotherapycentre.org

Parkinson's*

www.cwp.nhs.uk
and search for 'Parkinson's disease nurse specialist'

Diabetes*

www.coch.nhs.uk/all-services/diabetes.aspx

* Your GP or hospital can refer you to these services.

Support Groups

Breast Cancer

Breast Cancer Support Group for women with primary breast cancer: 01244 363 256

Stoma

www.colostomyassociation.org.uk
Click on 'The Directory' and 'Regional support groups'.

Working Age (Cancer)

SWAGG (Support for Working Age Guys and Girls). For more details contact Liz Taylor, Macmillan Support and Information Manager: 01244 364 948 or email: elizabeth.taylor18@nhs.net

Oesophageal and Stomach Cancer

www.gutsyguys.co.uk
contact@gutsyguys.co.uk

Prostate Cancer

Search Google for 'Wirral Prostate Cancer Support' and click top link.

Maggie's Centre

www.maggiescentres.org
Click on 'Our centres'. 0151 334 4301

Asbestos

Cheshire Asbestos Victims Support Group
<http://www.cavsg.co.uk/> • 01928 576 641

Chronic Obstructive Pulmonary Disease (COPD)

Breath Easy BLF helpline 0300 003 0555
www.blf.org.uk/BreatheEasy/Detail/Chester

Heart Failure

Chester Heart Support Group
www.chesterheartsupportgroup.co.uk

Parkinson's

Parkinson's Support Group
www.parkinsons.org.uk
Click on 'Support for you' and 'Support in your area'. Helpline 0808 800 0303

Dementia

www.alzheimers.org.uk
Click on 'Local information', search for 'Vale Royal' and click 'Befriending Cheshire West and Chester'. 01244 851 351

Motor Neurone Disease (MND)

www.mndassociation.org
and search for 'Cheshire branch'.

Stroke

www.cheshireweststrokesupportgroup.co.uk

Additional Support

Befriending services

<http://ash-worthtimebank.org.uk>
and click on 'PACS'.

Cinnamon Trust (pet care and walking)
www.cinnamon.org.uk

Age UK

www.ageuk.org.uk/cheshire
and click on 'Information & Advice'.

Transport Services

Patient transport

www.patienttransport.nwas.nhs.uk
and click on 'Make a Booking - Read more'.

Macmillan Transport Support Chester
07525 812 169

Carers

A carer is anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support (Carers Trust) and carers may find it helpful to contact organisations that provide support to carers.

www.carers.org/local-service/cheshire/
0800 085 0307
advice@cheshirecarerscentre.org.uk

Young Carers

<http://cheshireyoungcarers.org/>
0151 356 3176

Financial and Welfare Advice

Information and advice may be required on eligibility for benefits to support patients and carers.

Citizens Advice

www.adviceguide.org.uk • 03444 772 121

Dice Ltd.

6 Mercer Walk, Port Arcades, Ellesmere Port,
South Wirral, Cheshire, CH65 0AP
0151 355 1420 • diceinfo@btconnect.com

DIAL West Cheshire

Hamilton Place, Chester, CH1 2BH
01244 345 655
contactus@dialwestcheshire.org.uk

Mobility

Maintaining mobility and independence can be assisted by using organisations providing mobility aids.

Shopmobility

www.shopmobility.org.uk
Information is also available from DICE Ltd. or DIAL West Cheshire.

RADAR Keys

RADAR Keys offer disabled people independent access to locked public toilets around the country through the National Key Scheme:

<http://tinyurl.com/o9jw2h7>

Information is also available from DICE Ltd. or DIAL West Cheshire.

Blue Badges

www.cheshirewestandchester.gov.uk

Search for 'Blue Badge' and click on 'Blue badge parking permit'. Or call 0300 123 704

Ableworld

www.ableworld.co.uk

St David's Retail Park, Saltney, Chester, CH4 8SN
01244 675 608 • chester@ableworld.co.uk

RKS Occupational Therapy Service

Unit 4 Cheshire Oaks Trade Park, Stanney Mill Road, Little Stanney, Chester, CH2 4JZ
0151 356 7007 • www.rksot.co.uk

Ability Aware Store

The Pool Centre, New Grosvenor Road, Ellesmere Port, CH65 2HB • 0151 345 1265
www.abilityaware.com/index.php/stores/

Ross Care

140 Chester Road, Whitby, Ellesmere Port,
CH65 6SA
0151 355 9919 • ellesmere.port@rosscare.co.uk
www.rosscare.co.uk/retail-stores/

Self-care

Telecare

Telecare services use technology to help you live more independently at home and include things such as personal alarms and motion sensors.
www.cheshirewestandchester.gov.uk
and search for 'Telecare'.

Hospices

Hospices provide expert care for patients with life-limiting or terminal conditions and their friends and families.

Hospice of the Good Shepherd

www.hospiceofthegoodshepherd.com/how-we-help/ • 01244 851 091

St Luke's Hospice Winsford

www.stlukes-hospice.co.uk/how-we-can-help/patient-services/ • 01606 551 246

Halton Haven Hospice

www.haltonhavenhospice.co.uk
01928 712 728

Wirral Hospice St Johns

www.wirralhospice.org • 0151 334 2778

Care Homes

Information on care homes in West Cheshire:

www.cheshirewestandchester.gov.uk
and search for 'Care Homes' - select 'Find a care home in Cheshire and West Cheshire'. If looking specifically for a care home with nursing, search for 'Nursing Homes'.

Planning for the Future

Some people like to plan ahead to think about how they would like to be cared for in their final months of life.

Care Planning

www.nhs.uk/Planners/end-of-life-care/Pages/planning-ahead.aspx

Lasting Power of Attorney

www.nhs.uk/Planners/end-of-life-care/Pages/lasting-power-of-attorney.aspx

Advance Statement

www.nhs.uk/Planners/end-of-life-care/Pages/advance-statement.aspx

Making a will

www.gov.uk/make-will

Mental Capacity Act

www.nhs.uk/conditions/social-care-and-support-guide/pages/mental-capacity.aspx

Patient Advocacy Services

www.nhs.uk/Conditions/social-care-and-support-guide/Pages/advocacy-services.aspx

Do Not Attempt Cardiopulmonary Resuscitation

<http://tinyurl.com/nrldo2x>

Spiritual Care

www.chesterva.org.uk/tag/interfaith/

Practicalities following bereavement

www.hospiceofthegoodshepherd.com

Click on 'How we help' then 'Services', 'Bereavement services' and 'Directory of support'. Click on the link to download the booklet *Bereavement Support in Western Cheshire*.

Bereavement Services

Adult

www.hospiceofthegoodshepherd.com

Click on 'How we help' then 'Services', 'Bereavement services' and 'For adults'.

01244 853 193

bereavement@hospiceotgs.com

Children and Young People

www.hospiceofthegoodshepherd.com

Click on 'How we help' then 'Services', 'Bereavement services' and 'For Children and Young People'.

01244 851 104 • Reflect@hospiceotgs.com

Life After Bereavement - Bereavement Support

www.hospiceofthegoodshepherd.com

Click on 'How we help' then 'Services', 'Bereavement services' and 'Directory of support'.

Record sharing

Information about you is needed to enable healthcare professionals to deliver treatment and care. Sometimes information about you needs to be passed on to other agencies or organisations such as hospitals, GPs, district nurses, other health care professionals and social care. An example of this would be if you are receiving care at a hospital or being discharged from a care setting to support your care at home.

Anyone who receives this information is under a legal duty to keep it confidential and the Law strictly controls the sharing of some types of very sensitive personal information.

Health and Social Care Regulator

Care Quality Commission

www.cqc.org.uk

Consumer Champion

Healthwatch

www.healthwatchcwac.org.uk

Dying Matters

www.dyingmatters.org



HOSPICE
OF THE GOOD SHEPHERD

Countess of Chester Hospital



NHS Foundation Trust

**WE ARE
MACMILLAN.
CANCER SUPPORT**

Cheshire and Wirral Partnership



NHS Foundation Trust

Developed in partnership with the Hospice of the Good Shepherd, Macmillan Cancer Support, Countess of Chester Hospital NHS Foundation Trust and Cheshire and Wirral Partnership NHS Foundation Trust. Dedicated to the memory of **John Lavender** and all of our patients and carers.