

A-Z End of Life Care Resources



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Search 'Learning Disabilities Key Documents and Resources'

Produced by:

Gloucestershire Integrated Care Board

Gloucestershire Health and Care NHS Foundation Trust

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In Gloucestershire, we want to ensure the highest quality palliative & end of life care is available to all who need it irrespective of care setting, illness, age or diagnosis.

This A-Z of Palliative & End of Life Care Resources outlines:

- What palliative & end of life care information, leaflets and resources are available to support you in caring for people with learning disabilities
- What end of life care education and training is available and where/how you can access it
- What specialist palliative & end of life care support is available and how to access it

Key Messages:

I am supporting or caring for someone with a learning disability who has been diagnosed with a terminal illness:

1. Give the person every opportunity to express their priorities, wishes and preferences for care before death, as well as what they want to happen after they die. Start planning discussions early; there are easy-read resources in this guide to help you.
2. Symptom management can be more challenging with someone who has communication difficulties. Speak to someone who knows the person well to understand what is usual for this person. There are a range of tools that can help you (see Symptom Management section in the guide).
3. Last few days/hours -There are physical changes and signs that death is near; these may be upsetting for carers but do not appear to distress the person who is dying. These signs are a normal part of the dying process (See Dying section in the guide)

Where can I go for Support?

1. There are useful resources in this guide.
2. Does your organization have an 'End of Life Care Lead' or 'Champion' you can speak to? (see End of Life Care Leads section in the guide)
3. Hospices may be able to give you advice and support (see Hospices section in the guide)
4. The Specialist Palliative Care Telephone Advice and Support line is available 24/7 for professionals:

☎ 0300 422 5370

9.00 to 17.00 (Mon – Fri) call Community team

☎ 0300 422 2222

Any other time and ask for on-call Palliative Care

5. [A Personalised approach to Palliative, End of Life and Bereavement Care : NHS Gloucestershire ICB](#)

A

Advance Care Planning

Advance care planning is a process whereby an individual's wishes, preferences and priorities for care at end of life are discussed, recorded and communicated to key people involved in their care.

Leaflet: Thinking Ahead – My wishes for my Advance Care Plan

Easy Read Leaflet: [Making a plan for your health and care if you become very ill](#)

Advance Decisions to Refuse Treatment: A Guide for Health & Social Care Professionals – www.england.nhs.uk

[Advance-Decisions-to-Refuse-Treatment-Guide.pdf \(england.nhs.uk\)](#)



Advance Care Planning

[Planning Ahead – personalised care and support planning : NHS Gloucestershire ICB](#)

Advocacy

Advocates support individuals when making important decisions about their health and care choices - www.yourcircle.org.uk

[Health and Social Care Advocacy | YourCircle](#)

Age UK Gloucestershire

Support people in Gloucestershire to navigate later life, to remain independent at home and to connect with friends and the local community - www.ageuk.org.uk/gloucestershire/

[Welcome to Age UK Gloucestershire](#)

Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026 - www.england.nhs.uk

[ambitions-for-palliative-and-end-of-life-care-2nd-edition.pdf \(england.nhs.uk\)](#)

B

Bereavement

For most of us bereavement, grief and loss will be the most emotionally distressing experience we will ever face. How we grieve will be unique to every one of us, it is important to remember there is no 'right' or 'wrong' way to grieve.



Supporting People with Disabilities Coping with Grief and Loss - [www.easyhealth.org.uk/resources/Supporting People with Disabilities Coping With Grief and Loss | Easy Health](http://www.easyhealth.org.uk/resources/Supporting%20People%20with%20Disabilities%20Coping%20With%20Grief%20and%20Loss%20|%20Easy%20Health)

Easy Read – Your feelings when someone dies and what can help - MAC16322_ER_E05 – www.macmillan.org.uk

Easy Read – How You May Feel When Someone Dies – MAC16322 - [https://be.macmillan.org.uk/MAC16322 ER E04 How you may feel whe someone dies.pdf \(macmillan.org.uk\)](https://be.macmillan.org.uk/MAC16322_ER_E04_How_you_may_feel_whe_someone_dies.pdf)

Leaflet – Bereavement and Loss – practical guidance and support for bereaved people when somebody dies – GDH3702 – www.nhsglos.nhs.uk / Free End of Life Resources [GDH3702-Bereavement-and-loss.pdf](http://www.nhsglos.nhs.uk/GDH3702-Bereavement-and-loss.pdf)

Cruse Bereavement Support - www.cruse.org.uk

Bereavement resources [Bereavement Care & Support : NHS Gloucestershire ICB](#)

Best Interest Decisions

(See Mental Capacity)

C

Capacity

Capacity is having sufficient understanding and memory to comprehend situations which arise and being able to understand the nature, purpose and consequence of any actions entered into.

Capacity Assessment (Learning Disabilities)

Contact Gloucestershire Health and Care NHS Foundation Trust Learning Disability Service

Leaflet – Mental Capacity Act Resource Pack – www.mencap.org.uk
[mental capacity act resource pack 1.pdf \(mencap.org.uk\)](http://www.mencap.org.uk/mental_capacity_act_resource_pack_1.pdf)

Cancer Support

There is a variety of practical advice and support locally and nationally for people who have been diagnosed with cancer (or their family and friends).

Charlie's – Gloucester

<http://www.charlies.org.uk/>

Macmillan Cancer Support - www.macmillan.org.uk

[Cancer Information And Support | Macmillan Cancer Support](#)



Easy-Read – resources from Macmillan - <https://be.macmillan.org.uk/>
[be.macmillan - Easy read titles](#)

Maggie's Centre – Cheltenham - www.maggies.org

[Maggie's Cheltenham | Maggie's \(maggies.org\)](#)



Marie Curie

www.mariecurie.org.uk/



Carers

Leaflet – Support for Carers in Gloucestershire who are Looking after Someone at End of Life
- www.nhsglos.nhs.uk

<https://www.nhsglos.nhs.uk/wp-content/uploads/2022/01/GDH3216-REV-APRIL-2019.pdf>

Gloucestershire Carers Hub -
<https://gloucestershirecarershub.co.uk/>

Continuing Health Care

Continuing healthcare (CHC) is the name given to a package of care that is arranged and funded by the NHS for adults outside of hospital that have ongoing complex or intense or unpredictable healthcare needs - www.nhsglos.nhs.uk

<https://www.nhsglos.nhs.uk/your-health-services/funding-treatment/continuing-healthcare/#link-intro>



If a person is rapidly deteriorating and may be entering a terminal phase they may be eligible for CHC Fast-track funding to enable their care needs to be urgently met.

Contact: 0300 421 0303 or GLICB.CHC-SPA-Team@nhs.net

Consent

In law, voluntary agreement with an action proposed by another. Consent is an act of reason; the person giving consent must be of sufficient mental capacity and be in possession of all essential information in order to give valid consent. A person who is an infant, is mentally incompetent, or is under the influence of drugs is incapable of giving consent. Consent must also be free of coercion or fraud.

<https://medical-dictionary.thefreedictionary.com/> -
[Consent | definition of consent by Medical dictionary \(thefreedictionary.com\)](https://medical-dictionary.thefreedictionary.com/consent)

Consent to treatment
<https://www.nhs.uk/conditions/consent-to-treatment/>

Consent Guidelines (Learning Disability Health Facilitation Team)
- www.ghc.nhs.uk/Key Documents & Resources

[LD-consent-poster-2022.docx \(live.com\)](#)

Communication

The Hospital Communication Book - [www.ghc.nhs.uk /Key Documents & Resources](http://www.ghc.nhs.uk/Key Documents & Resources)

[Hospital Communication Book Section One.pdf](#)
[Hospital Communication Book Section Two.pdf](#)

D

Dignity

Treating every individual with respect, enabling them to maintain independence, choice and control. <http://www.dignityindying.org.uk/>



Dying

As we die there are physical changes and signs that death is approaching.

Leaflet: [GCCG-Caring-for-someone-at-the-end-of-their-life.pdf](#)

Easy Read – End of Life - <https://be.macmillan.org.uk/MAC16343The-end-of-life> (macmillan.org.uk)

Easy Read – Changes that can Happen at the End of Life - <https://cdn.macmillan.org.uk/mac16303-er-e04-changes-at-the-end-of-life-pdf> (macmillan.org.uk)

E

E- Learning

End of Life Care e-learning - www.e-lfh.org.uk
[End-of-life Care For All \(e-ELCA\) - elearning for healthcare \(e-lfh.org.uk\)](#)

End of Life Care Education

GHC staff – please log-on to Care2Learn for current end of life care education and training opportunities

- Proud to care: [End of Life / Palliative Care | Proud to Care Gloucestershire](#)
- G-Care – [End of Life / Palliative Care | Education & Training | G-care](#)
- Link to PEOLC webpages (professional section to be added soon) [A Personalised approach to Palliative, End of Life and Bereavement Care : NHS Gloucestershire ICB](#)



End of Life Care Leads

If you work at the NHS Trusts below you can contact your End of Life Care lead for advice and support:

Gloucestershire Health and Care NHS Foundation Trust
Debbie Williams (Debbie.williams@ghc.nhs.uk)

Gloucestershire Hospitals NHSFT
Sam White (samantha.white4@nhs.net)

Gloucestershire End of Life Care Strategy
https://www.nhsglos.nhs.uk/wp-content/uploads/2023/06/End-of-Life-StrategyFinal_22pdf.pdf

F

Faith and Culture

The Community Partnerships team and IT team from Gloucestershire Care Services have developed a 'Cultural App' to support health and care colleagues to have conversations with service users about how to best understand and support their spiritual and cultural needs. Covers areas such as food, death, key beliefs and observances:

<https://culturalawareness.glos-care.nhs.uk/>
[Communities - Cultural Awareness \(glos-care.nhs.uk\)](#)

Funerals

A funeral is a ceremony connected with the burial, cremation, etc. of the body of a dead person, or the burial (or equivalent) with the attendant observances. Funerary customs comprise beliefs and practices used by a culture to remember and respect the dead, from interment itself, to various monuments, prayers, and rituals undertaken in their honor.

Coroner's Service, Burials & Cremations and Registering a Death

www.gloucestershire.gov.uk
[Births, marriages, deaths and civil partnerships - Gloucestershire County Council](#)

Easy Read – Going to a Funeral when Someone Dies - <https://cdn.macmillan.org.uk/mac16311-er-e04-going-to-funeral-pdf> (macmillan.org.uk)



G

Gold Standards Framework

Gold Standards Framework is a systematic common-sense approach to formalising best practice, so that quality end of life care becomes standard for every patient. It helps clinicians identify patients in the last years of life, assess their needs, symptoms and preferences and plan care on that basis, enabling patients to live and die where they choose. This approach is used by some GP practices in Gloucestershire.

Gold Standard Framework
- <https://goldstandardsframework.org.uk/>

[Welcome to Gold Standards Framework](https://goldstandardsframework.org.uk/)



H

Health

Making Health Information Easier – www.apictureofhealth.southwest.nhs.uk/

[Home | A Picture of Health | Making Health Information Easier \(southwest.nhs.uk\)](http://www.apictureofhealth.southwest.nhs.uk/)

Homelessness

Homelessness and end of life care: Practical information and tools to support the needs of homeless people who are approaching the end of life, and those who are bereaved

- www.mungos.org/publication

[Homelessness and end of life care - St Mungo's \(mungos.org\)](http://www.mungos.org/publication)

Homeless Healthcare Team in Gloucestershire - www.yourcircle.org.uk

[Homeless Healthcare Team and Special Allocation Scheme | YourCircle](http://www.yourcircle.org.uk)

Hospices

Hospices provide specialist care and a range of holistic (physical, psychological, spiritual and social) support to people with a life-limiting illness, their carers and families.

There are 6 hospices in Gloucestershire:

Leckhampton Court Hospice (Cheltenham) provides in-patient hospice beds, day hospice care and hospice at home care (Cheltenham, Gloucester and Tewkesbury)

Email: leckhampton@sueryder.org

<http://www.sueryder.org/care-centres/hospices/leckhampton-court-hospice>

Great Oaks Hospice (Coleford) provides day hospice care and hospice at home care (Forest of Dean)

Email: clerical@great-oaks.org.uk

<http://www.great-oaks.org.uk/index.html>

Longfield (Minchinhampton) provides day hospice care and hospice at home care (Stroud and Berkeley, Cotswold's and Gloucester)

Email: info@longfield.org.uk

<https://www.longfield.org.uk/>

Kate's Home Nursing

Kate's Home Nursing provides professional, compassionate, specialist nursing 'hospice at home' care

Email: info@kateshomenursing.org

<https://www.kateshomenursing.org/>

Campden Home Nursing

Email: info@campdenhomenursing.org

<https://www.campdenhomenursing.org/>

Friends of Fairford & Lechlade Communities

Email: nursing@friendsoffairford.org.uk

https://www.friendsoffairford.org.uk/home_nursing.htm

Hospital

Hospital Passport - www.ghc.nhs.uk /Key Documents & Resources

[Key documents and resources > Glos Health & Care NHS Foundation Trust](http://www.ghc.nhs.uk)

I

Identification of End of Life (last 12 months)

A handy 1-page holistic guide to prognostic indicators for GP's to help identify patients who may be considered as end of life (last 12 months). 1% of the population dies each year. The Supportive and Palliative Care Indicators Tool (SPICT): www.spict.org.uk

[SPICT – Supportive and Palliative Care Indicators Tool](http://www.spict.org.uk)

J

Just in Case Boxes

Just in Case Boxes are available for GP's to prescribe in the Forest of Dean and are being rolled out across Gloucestershire. This is a box containing anticipatory medication that a person may need for the main symptoms at end of life (pain, nausea, secretions, agitation). It is kept in the persons home 'just in case' it may be needed and is particularly useful at evenings and weekends if urgent or emergency services have been called out. For more information contact glccg.endoflifeteam@nhs.net

K

Kings Fund

The Kings Fund is a charity that seeks to understand how the health system in England can be improved. They help to shape policy, transform services and bring about behavioral change - www.kingsfund.org.uk

[Ideas that change health and care | The King's Fund](http://www.kingsfund.org.uk)
([kingsfund.org.uk](http://www.kingsfund.org.uk))



L

Learning Disabilities

Learning Disability Services in Gloucestershire - www.ghc.nhs.uk

[Learning disabilities > Glos Health & Care NHS Foundation Trust \(ghc.nhs.uk\)](#)

Learning Disability Health Facilitation Leaflet - [www.ghc.nhs.uk /Key Documents & Resources](http://www.ghc.nhs.uk/Key Documents & Resources)

[Health Facilitation > Glos Health & Care NHS Foundation Trust](#)

Leaflet – Your Next Patient has a Learning Disability: A Practical Guide for Healthcare Professionals - www.csp.org.uk

[Learning disability guide download.pdf \(csp.org.uk\)](#)

LeDeR

Learning from lives and deaths - People with a learning disability and autistic people (LeDeR) is an NHS England service improvement programme which aims to improve care, reduce health inequalities and prevent premature mortality of people with a learning disability and autistic people by reviewing information about the health and social care support people received. We use learning from those reviews to make improvements across the health and social care system.

These supporting end of life resources can help professionals caring for people with learning disabilities.

Easy Read ReSPECT Leaflet - [Easy read ReSPECT-3 leaflet 1- Introduction.pdf](#)

[NHS England » Addressing inequalities in palliative and end of life care](#)

Useful information and resources on how to create life stories for people with dementia and a learning disability - from the charity MacIntyre. - <https://www.macintyrecharity.org/our-approach/resources/life-story-wellbeing-for-life/>

Marie Curie – palliative care for people with a learning disability – [Palliative care for people with learning disabilities | Marie Curie](#) This guidance is for healthcare professionals on understanding a person's needs and improving their quality of life in palliative care. They also have a series of easy read materials for people with a learning disability and carers caring for someone who is dying

Resources and tips for commissioners, service providers and health and social care staff including an ambition to view people holistically when providing end of life care. - Delivering high quality end of life care for people who have a learning disability
– <https://www.england.nhs.uk/wp-content/uploads/2017/08/delivering-end-of-life-care-for-people-with-learning-disability.pdf>

Palliative Care for People with Learning Disabilities Network- [Home - PCPLD Network](#)
Resources and easy read materials about palliative care, advanced planning and bereavement support.

Learning Disability England: DNR: A guide for understanding your rights and challenging decisions - <https://www.learningdisabilityengland.org.uk/news/latest-news/dnar-a-guide-for-understanding-your-rights-and-challenging-decisions> Guide is to help people with a learning disability, their families and support staff understand DNRs.

GP mythbuster 105: Do not attempt cardiopulmonary resuscitation (DNACPR) - Care Quality Commission - This myth buster aims to reduce confusion clarify, signpost and share guidance for providers. It aims help providers manage and maintain effective oversight of DNACPR decisions.

<https://www.england.nhs.uk/publication/universal-principles-for-advance-care-planning/> Six high level principles for advance care planning in England. It is for the person, those important to them, practitioners and organisations involved in supporting advance care planning conversations and honouring their outcomes.

About LeDeR

LeDeR Resource Bank - a place where you can find lots of important information about the main health conditions that people with a learning disability and autistic people experience and what reasonable adjustments you can make to help people.

Long Term Conditions

A long-term condition is an illness that cannot be cured but can usually be controlled with medicines or other treatments. Examples of long-term conditions include arthritis, asthma, diabetes, epilepsy, angina, heart failure, and high blood pressure

Library Resources

For NHS staff - <https://library.nhs.uk/>
NHS Knowledge and Library Services -

NHS Futures: [FutureNHS Home - FutureNHS Collaboration Platform](#) (register to access)

M

Medical Examiner

The role of a Medical Examiner

The law has changed in how to obtain a death certificate when someone dies. This means before you can register the death using the certificate issued by either the GP or hospital caring for the patient, a Medical Examiner must authorise its accuracy and release. Medical Examiners are senior doctors who are independent of the care but review the circumstances leading to death and offer bereaved relatives/carers an opportunity to understand the wording on the certificate and where appropriate, raise concerns with care. Someone in the Medical Examiner team will contact the person who nominated themselves to be available for this discussion.

Mental Capacity

Mental Capacity Act (2005) - www.legislation.gov.uk

[Mental Capacity Act 2005 \(legislation.gov.uk\)](http://www.legislation.gov.uk)

Easy Read – Mental Capacity Act - www.local.gov.uk

[Mental Capacity Act 2005: An easy read guide \(local.gov.uk\)](http://www.local.gov.uk)

N

Newsletters

Learning from Deaths (LeDeR) newsletter

www.inclusiongloucestershire.co.uk/engagement - [LeDeR - Inclusion Gloucestershire](http://www.inclusiongloucestershire.co.uk/engagement)
www.leder.nhs.uk - [LeDeR - Home](http://www.leder.nhs.uk)

O

Office of Public Guardian

The Office of the Public Guardian (OPG) protects people in England and Wales who may not have the mental capacity to make certain decisions for themselves, such as about their health and finance. OPG is an executive agency, sponsored by the Ministry of Justice.



Office of the
Public Guardian

<https://www.gov.uk/government/organisations/office-of-the-public-guardian>

See also Mental Capacity

Orange Folder – “What Matters to Me”

The “What Matters to Me” (orange) folder is universally recognized by health and care professionals across Gloucestershire, as the vessel to hold your personalized care and support plans. They will “ask and check” whether you own the folder with personalized care & support plans to offer to arrange for the plans to be developed and issue a folder.

The folder has 3 internal wallets labelled:

- All About Me
- Goals for Me
- Important to Me



If you are living with a complex long-term condition, you will be invited to complete your personalised care and support plans. There are numerous paper formats available including:

- All About Me (Children & Young People)
- My Health Passport (Adults with Learning Disability)
- MyLife My Plan (Adults)
- Me at My Best Plan (Older People)
- ReSPECT Plan (All-aged)

The image shows two sample forms. The first is 'Me At My Best', which is a form for older people to discuss their care and support. The second is 'ReSPECT', which is a form for people with long-term conditions to discuss their treatment and care in an emergency.

P

Patient Advice and Liaison Service

The Patient Advice and Liaison Service (PALS) offer confidential advice, support and information on health-related matters. They provide a point of contact for patients, their families and their carers.

Gloucestershire Health and Care NHS Foundation Trust - www.ghc.nhs.uk/get-in-touch
[Give us your views > Glos Health & Care NHS Foundation Trust \(ghc.nhs.uk\)](http://www.ghc.nhs.uk/get-in-touch)

Gloucestershire Hospitals NHSFT PALS - www.gloshospitals.nhs.uk/contact-us
[Feedback and complaints \(gloshospitals.nhs.uk\)](http://www.gloshospitals.nhs.uk/contact-us)

Gloucestershire Integrated Care Board - www.nhsglos.nhs.uk/have-your-say
[PALS \(feedback and enquiries\) : NHS Gloucestershire ICB \(nhsglos.nhs.uk\)](http://www.nhsglos.nhs.uk/have-your-say)



Personalised Care

A personalised care and support plan records information based on what is usual for you 'all about me' and how you live at home with your health condition and/or unique wellness 'me at my best'.

Advance care planning will help define your priorities and preferences for future care, particularly important during an emergency situation and helping with the uncertainty about a health prognosis.

Plans will be developed with you, supported by your family/carer/advocate and health & care professional.

Palliative Care

Palliative care is the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families.

Referral - Specialist Palliative Care in Gloucestershire is delivered by Gloucestershire Hospitals NHSFT. To make a referral: www.gloshospitals.nhs.uk/our-services
[Specialist Palliative Care \(gloshospitals.nhs.uk\)](http://www.gloshospitals.nhs.uk/our-services)

Advice and Support - The Specialist Palliative Care Telephone Advice and Support line is available 24/7 for professionals:

☎ 0300 422 5370

9.00 to 17.00 (Mon – Fri) call Community team

☎ 0300 422 2222

Any other time and ask for on-call Palliative Care

Planning

Easy Read - My End of Life Plan - www.ghc.nhs.uk/Key Documents & Resources
[My-End-of-Life-Plan-January-2017.doc \(live.com\)](http://www.ghc.nhs.uk/Key Documents & Resources)

Age UK - Planning and Support for the End of Life
www.ageuk.org.uk/globalassets/age-uk/documents/ageukig51_thinking_about_end_of_life_inf.pdf



Q

Quality Standards

There are two NICE Quality Standards for End of Life Care for adults aged 18+.

Quality Standard 13: End of Life Care - www.nice.org.uk/guidance
[Overview](#) | [End of life care for adults](#) | [Quality standards](#) | [NICE](#)

Quality Standard 144: Care of Dying Adults in the Last Days of Life - www.nice.org.uk/guidance
[Overview](#) | [Care of dying adults in the last days of life](#) | [Quality standards](#) | [NICE](#)

R

ReSPECT

Gloucestershire NHS Trusts and partners have adopted the Recommended Summary Plan for Emergency Treatment (ReSPECT) process. This is a process that allows people to record their wishes about how they would like to be treated in a medical **emergency** when they may not be able to communicate.

Easy Read guides to the ReSPECT process can be found here

www.resus.org.uk/respect/respect-resources
[ReSPECT Resources](#) | [Resuscitation Council UK](#)

S

Safeguarding

Gloucestershire Safeguarding Adults Board - www.gloucestershire.gov.uk/gsab
[Safeguarding Adults in Gloucestershire](#) - [Safeguarding Adults in Gloucestershire](#)

Social Care

Education, training, knowledge and skills sets for Social Care
www.skillsforcare.org.uk

Summary Care Record (GP Patient Record)

The Summary Care Record is an electronic record of patient information created from their GP record, including wishes and preferences for end of life care. Access to view a patient's summary care record has been rolled out across Gloucestershire -

<https://digital.nhs.uk/services>

[Summary Care Records \(SCR\) - information for patients - NHS Digital](#)

Symptom Management

UK Health Security Agency (formerly Public Health England) have produced a guide on how social care staff can recognise and manage pain in people with learning difficulties

<https://assets.publishing.service.gov.uk/government/uploads>

[How social care staff can recognise and manage pain in people with learning disabilities \(publishing.service.gov.uk\)](#)

T

Transitioning (GHFT process and not GHC process at this time)

Moving from Children's Health Care to Adult Health Care - www.ghc.nhs.uk

[Moving from Childrens Services to Adult Services Transition GHPI1169 01 23.pdf](#)

U - Z

Young People with Cancer

There are a range of charities who support young people with cancer.

Teenage Cancer Trust - www.teenagecancertrust.org

[Teenage Cancer Trust | UK Cancer Charity](#)

CLIC Sargent - www.younglivesvscancer.org.uk

[Young Lives vs Cancer - we'll face it all, together](#)