

Cancer52 – published materials on rare and less common cancers



July 2024

Cancer52 is an alliance of over 110 patient charities united in their vision of a better future for everyone affected by rare and less common cancers. We aim to promote improved diagnosis, treatment and support for those affected by rare and less common cancers.

Rare and less common cancers are defined as all cancers outside of the four most common cancers. There are over 200 different types of cancer, the majority of these are rare and less common cancers. In the UK, 47% of all cancer diagnoses and 55% of all cancer deaths are from rare or less common cancers. That means that every year around 180,000 people will be diagnosed from a rare or less common cancer and more than 92,000 people will die from a rare or less common cancer.¹

People with rare and less common cancers face unique and often ingrained challenges because of the broad scope of types of cancers, the diversity of rare and less common patient profiles including children and young people, and by definition, small patient populations. People with rare and less common cancers can experience inequalities in accessing care and treatment and face further inequalities linked with characteristics including deprivation, ethnicity, gender, age and disability.

These characteristics are associated with differences in prevalence of cancer risk factors, cancer incidence rates, experience of care and ultimately survival outcomes. Every cancer is different, but there are often shared challenges which affect people with rare or less common cancers including poorer patient experiences, delays to diagnosis and under investment. There can also be barriers to accessing specialist care and new, more effective, treatments.

This resource library brings together published materials from some of Cancer52's members to help NHS Community Connectors and others improve early diagnosis of rare and less common cancers, and ensure that patients can receive better support and more effective treatments.

¹ Cancer52 (2024) [The other half: a manifesto to transform outcomes for people with rare and less common cancers](#)

	Signs and symptoms information	Tailored information for specific people and communities
Appendix		
Pseudomyxoma Survivor	About pseudomyxoma peritonei	
Bladder		
Action Bladder Cancer UK	Symptoms of bladder cancer	
Fight Bladder Cancer	Bladder cancer posters	
The Urology Foundation	Urology cancers	
UCARE	Education and awareness	
Bone		
Bone Cancer Research Trust	Symptoms of bone cancer	
Sarcoma UK	Diagnosing sarcoma What is sarcoma? Education and training	Booklets can be translated into different languages if requested from Sarcoma UK's website.
Brain		
Brain Tumour Research	Brain tumour symptoms	
Brainstrust	Brain tumour signs and symptoms	
The Brain Tumour Charity	Brain tumour signs and symptoms	
Colorectal		
GIST Cancer UK	GIST patient booklet	

Pseudomyxoma Survivor	About pseudomyxoma peritonei	
Endocrine		
British Thyroid Foundation (BTF-thyroid)	Thyroid cancer	
Butterfly Thyroid Cancer Trust (BTCT)	About thyroid cancer	
Gastrointestinal		
GIST Cancer UK	GIST patient booklet	
Germ Cell		
It's in the Bag	Awareness	
It's on the Ball	How to check yourself for testicular cancer	It's on the Ball delivers awareness sessions tailored for SEND young adults. Their SEND resources are freely available to teachers on the TES website.
Gynaecological		
Jo's Cervical Cancer Trust (charity has now closed, but resources still available)	Symptoms of cervical cancer	Cervical screening for people with a learning disability Cervical screening after sexual violence Cervical screening for trans men and/or non-binary people Jo's Cervical Cancer Trust has a 'Choose your language' tool on their website, which will translate all pages.
Ovacome, Ovarian Cancer	The symptoms of ovarian cancer	Support in other languages
Ovarian Cancer Action	Ovarian cancer symptoms Raise awareness of ovarian cancer	Information on genetic testing for ovarian cancer available in multiple languages

	Hereditary cancer risk tool	
Target Ovarian Cancer	Symptoms of ovarian cancer	
The Eve Appeal	Probably nothing - video series	
Wellbeing of Women	Health information – gynaecological cancers	
Womb Cancer Info	Symptoms of womb cancer	
Womb Cancer Support UK	What is womb cancer?	
Haematological		
Blood Cancer UK	Blood cancer signs and symptoms	
British Lymphology Society (BLS)	About lymphoedema - video	
Leukaemia Care	Symptoms of leukaemia	Provides language information through World Leukaemia Day
Leukaemia UK	Signs and symptoms of leukaemia	
Lymphoma Action	Symptoms of lymphoma Lymphoma animation	
MDS (Myelodysplastic Syndromes) UK Patient Support Group	MDS symptoms	
Myeloma UK	Symptoms and complications of myeloma	
WMUK	Waldenstrom's macroglobulinaemia - symptoms	
Head and Neck		
Oracle Head and Neck Cancer UK	Signs and symptoms	

Kidney		
Action Kidney Cancer	What are the symptoms of kidney cancer?	Easy read information Help sheets written by patients for patients
Kidney Cancer UK	Symptoms of kidney cancer	
The Urology Foundation	Urology cancers	
UCARE	Education and awareness	
Liver, Gallbladder, Bile Tract		
AMMF – The Cholangiocarcinoma Charity	Patient organisation resources	
GUTS	Patient information leaflets	
Lung		
ALK Positive Lung Cancer	Collated resources	
Male Cancer		
Baggy Trousers UK	Check your nuts	
It's in the Bag	Awareness	
It's on the Ball	How to check yourself for testicular cancer	It's on the Ball delivers awareness sessions tailored for SEND young adults. Their SEND resources are freely available to teachers on the TES website.
Orchid Cancer Appeal	Awareness and information	
The Urology Foundation	Urology cancers	

UCARE	Education and awareness	
Mesothelium		
Mesothelioma UK	Symptoms of mesothelioma	
Neuroendocrine		
Neuroendocrine Cancer UK	Symptoms of neuroendocrine cancer	
Oesophageal		
GIST Cancer UK	GIST patient booklet	
Heartburn Cancer UK	Symptoms and related conditions	
Paediatric		
Childhood Eye Cancer Trust (CHECT)	What is retinoblastoma?	Signs & symptoms information available in other languages , including Polish and Romanian.
Children's Cancer and Leukaemia Group (CCLG)	Signs and symptoms of childhood cancer Referral guidance for symptoms of childhood cancer	
Grace Kelly Childhood Cancer Trust	Signs and symptoms of childhood cancer materials and video	Currently translating materials into other languages.
Solving Kids' Cancer	Symptoms of neuroblastoma	
Teenage Cancer Trust	Signs of cancer	
Pancreatic		
Pancreatic Cancer Action	Pancreatic cancer symptoms	

Pancreatic Cancer UK (PCUK)	Signs and symptoms of pancreatic cancer Do you know the symptoms of pancreatic cancer?	All information can be accessed in other languages and for a range of accessibility needs using Recite Me (under Accessibility tools). Pancreatic Cancer UK is currently developing a visual guide for this. Other formats include information videos and printed booklets and leaflets. Information can also be provided in Braille, audio and large print on request. They also have four guides in Easy Read format. Their tailored emails are designed to help avoid overwhelm for users with poor mental health or other needs. Information in Pancreatic Cancer UK's app, Medli, supports people who may prefer not to interact with our support in person, e.g. people with autism.
Penile		
Orchid Cancer Appeal	Awareness and information	
The Urology Foundation	Urology cancers	
UCARE	Education and awareness	
Sarcoma		
Chordoma UK	Chordoma spinal cancer symptoms	
GIST Cancer UK	GIST patient booklet	
Sarcoma UK	Do I have sarcoma?	
The Chris Lucas Trust	What is Rhabdomyosarcoma?	
Skin		

Melanoma Focus	Signs and symptoms of melanoma	
Melanoma UK	Skin check toolkit	
Supportive & Palliative		
OUTpatients	Cervical screening – remove the doubt Cervical screening – My Cervix, My Service Chest Check 101 Information for people who are intersex Cancer risk and screening - information for people who are transgender, non-binary and gender-diverse	All resources are LGBTIQ+ specific
Testicular		
Baggy Trousers UK	Check your nuts	
It's in the Bag	Awareness	
It's on the Ball	How to check yourself for testicular cancer	It's on the Ball delivers awareness sessions tailored for SEND young adults. Their SEND resources are freely available to teachers on the TES website.
Orchid Cancer Appeal	Awareness and information	
The Urology Foundation	Urology cancers	
UCARE	Education and awareness	
Thoracic		
Mesothelioma UK	Symptoms	
Thymic		

ThymicUK	Thymic cancer leaflet and infographic	
Thyroid		
British Thyroid Foundation (BTF-thyroid)	Thyroid cancer	
Butterfly Thyroid Cancer Trust	About thyroid cancer	
Urogenital		
Action Bladder Cancer UK	Bladder cancer symptoms guide	
Action Kidney Cancer	What are the symptoms of kidney cancer?	Easy read information Help sheets written by patients for patients
Fight Bladder Cancer	Signs and symptoms	
Kidney Cancer UK	Symptoms of kidney cancer	
The Urology Foundation	Urology cancers	
UCARE	Education and awareness	
VHL UK/Ireland	VHL awareness bundle	
Young People		
Grace Kelly Childhood Cancer Trust	Signs and symptoms of childhood cancer materials and video	Currently translating materials into other languages.
Teenage Cancer Trust	Signs of cancer	