The ROYAL MARSDEN

NHS Foundation Trust

Accessing Support: Talking to Children About Your Cancer

It can be difficult to talk to children and teenagers about cancer, but it is important to give them an opportunity to talk openly about any fears or worries they may have. Not talking to children may lead to them feeling scared or confused, especially as children can often realise that something unusual is happening, even if they have not been told explicitly. Being open with children provides them a space to ask questions and share how they feel. You may want to speak to a psychologist or your CNS to process your own feelings before talking to your children, or to get advice about how to manage these potentially difficult conversations with children.



about now to manage these potentially difficult conversations with children.

The Royal Marsden has collaborated with The Fruit Fly Collective to produce some short videos that may get you started with ideas about how to talk to your children, and how to support them if you or someone they know has cancer:

https://patientinfolibrary.royalmarsden.nhs.uk/cancer-and-your-family

Below is a list of organisations who may be able to offer you some support, as well as some resources that you may find helpful to read/listen to. The range and quality of services/support available from such organisations may vary. This list has been gathered as signposting only, and The Royal Marsden cannot guarantee the accuracy of the information provided by an organisation listed or the quality of their services.

If you have any questions or would like further advice/guidance about where to seek specialist help in your local area, you can speak with a member of your Royal Marsden treatment team or the Adult Psychological Support Service.

Brain Tumour Charity - Jack's Animations

A series of animations designed for children led by the character of "Jack" and his family. The video explains brain tumours, scans, and different types of treatments using childappropriate language.

Website link: <u>https://www.thebraintumourcharity.org/living-with-a-brain-tumour/get-support/children-and-families-service/support-families/animations-explaining-brain-tumours/</u>



Breast Cancer Now's "Talking to your children about breast cancer" (Booklet)

Covers topics such as "finding the right words" with sections for discussing the matter with children who have learning disabilities, managing the child's reaction, and informing the child's school.

Website link: Talking with children about breast cancer | Breast Cancer Now

Cancer Support Community "What do I tell the Kids?" (Booklet)

A guide to managing the complex and often difficult conversations parents with cancer have with their children. It explores how children of different ages may understand and react to cancer, how to prepare for having the conversation, and tips on delivering it in a sensitive and effective way (timing, language, physical presences, and answering common questions).

Website link: <u>https://www.cancersupportcommunity.org/sites/default/files/d7/document/fsac_what_do_i_tell_the_kids.pdf</u>

The Ella Dawson Foundation

A charity offering support to young adults aged 18-29 and their families. They can offer free online counselling as well as exercise and nutritional advice.

Website link: https://elladawsonfoundation.org.uk/about-us

Fruit Fly Collective Video: Telling Your Children You Have Cancer

A video which explains why it is important for adults to talk to their children about their cancer diagnosis and provides advice on preparing for the conversation, finding the right place and way to deliver it, tips for wording, and how to answer any potential questions. It also explores understanding and potential reactions at different ages, including tips for managing these.

Website link: <u>https://www.youtube.com/watch?v=2DYBKKbE2Lg&feature=emb_logo</u>

Jigsaw South East

A charity which offers information, advice and guidance to help support bereaved children and young people and those facing the death of a loved one. Referrals can be made by a healthcare professional or directly via families on their website. Jigsaw also has a helpline open between 9.30am and 12.30pm on weekdays: **01342 313895**

Website link: https://www.jigsawsoutheast.org.uk/



Macmillan "Talking to Children and Teenagers When an Adult Has Cancer" (Booklet)

Explores the benefits of talking openly with children about cancer with advice on starting the conversation, explaining cancer in an understandable way (appropriate to age or learning disability), and finding the right place and time for this initial talk. Resources for supporting children and managing changes in the family dynamic/routine are included.

Website link:

https://be.macmillan.org.uk/downloads/cancerinformation/LivingWithAndAfterCancer/M AC5766 E04 N talktochildren p03 lowres 20190815 EC.PDF

Macmillan "Understanding Children and Teenagers' Reactions" Information Site

Information on capacity for understanding cancer at different ages (0-18yrs), how to explain cancer to them in an age-appropriate way, and what you can do to help them deal with the situation.

Website link: <u>https://www.macmillan.org.uk/cancer-information-and-</u> <u>support/diagnosis/talking-about-cancer/understanding-children-and-teenagers-reactions</u>

Macmillan Youth Line

A support line for young people (aged 12 to 21) who are affected by cancer – either that of a family member or if they are ill themselves.

Helpline: 0808 808 0800 - open Monday to Friday, 9am to 10pm

Email: youthline@macmillan.org.uk

Website link : <u>http://www.macmillan.org.uk/information-and-support/audience/teens-young-adults.html</u>

National Cancer Institute "When your parent has cancer: a guide for teenagers" (Booklet)

Aims to help teenagers confront the realities and struggles of a parent receiving a cancer diagnosis. Topics include finding support, self-care, managing personal/emotional/family changes, how they can help their parent, and handling the post-treatment period.

Website link: <u>https://www.cancer.gov/publications/patient-education/when-your-parent-has-cancer.pdf</u>



Parenting with Cancer

A support service offering coaching programmes, workshops, parenting tools, coping strategies, peer to peer support, family activities, and other resources. The website is regularly updated with resources and opportunities for parents trying to navigate their cancer diagnosis.

Website link: www.parentingwithcancer.org

Rip Rap: When a parent has cancer

Website developed specifically for teenagers who have a parent with cancer. Offers several information pages covering different types of cancer diagnoses and treatments, as well as advice on how to speak to one's parents, friends, and school about cancer. There are also support pages covering topics ranging from how to live with and beyond cancer, to how to manage bereavement. Many stories submitted by teenagers are included on the website in both written, audio, and video form and there is a chat forum that enables individuals to connect with others who are going through the same thing. There is also a section where users can submit a question to a qualified cancer nurse.

Website link: <u>http://www.riprap.org.uk/support/living_with_cancer/talking_about_cancer.asp</u>

Ruth Strauss Foundation

A charity which provides emotional support for families to prepare for the death of a parent from cancer.

Website link: https://ruthstraussfoundation.com/

The Royal Marsden - 'Talking to Children About Cancer' Workshop

The Royal Marsden Adult Psychological Support Service (APSS) offers an online information workshop for parents who feel unsure of whether, or how, to talk to their children about their illness. The workshop is facilitated by staff who specialise in working with families. This one-off group session is a place for parents to ask questions about how to share information about their illness with their children, and to receive ideas from professionals, as well as other parents.

For more information call: 0207 808 2777/ 0208 667 3006

Or email: <u>Psychological.supportadmin@rmh.nhs.uk</u>

Trekstock "Parenting and Cancer" Information page

Explains the benefits of talking to children about one's cancer diagnosis and provides a handful of tips on how to broach the subject. Also links a series of YouTube videos going into further depth in talking to children and adolescents about cancer, as well as several helpful book titles.



Website link: Parenting with cancer

NHS

Winston's Wish

This charity provides information, on-demand services, bereavement support and counselling for young people experiencing grief, and can also support adults who are caring for young grieving people.

Website Link: https://www.winstonswish.org/

Winston's Wish also has specific informational videos for adults, for example <u>"As Big as It Gets: Supporting a Child When a Parent is Seriously Ill"</u>, which provides advice on how parents might explain serious illness to their children alongside a range of ideas on how to make the child(ren) feel involved in what is happening.

Books for Children – comprehensive booklist available upon request

"A Dragon in Your Heart" by Sophie LeBlanc

A short, explanatory children's picture book written by Sophie LeBlanc following her own experiences of explaining cancer to her very young daughter. Using pictures and short descriptions, it attempts to explain cancer to children as clearly as possible.

Website link: <u>https://www.amazon.co.uk/Dragon-Your-Heart-Sophie-Leblanc/dp/1853027014</u>

"Can I Still Kiss You? Answering Your Children's Questions About Cancer" by Neil Russell

A book by Neil Russell written based on his experiences of speaking to his own children about his cancer diagnosis. Chapter by chapter, the book explores a series of questions and answers related to diagnosis, surgery, and radiation and chemotherapy before and after treatment, all the while providing parents with advice on how to communicate these experiences with their children. There is also additional space reserved in the back of the book for parents and children to use as a sort of "message board" for communicating worries, fears, and responses to one another.

Website link: https://www.amazon.co.uk/Can-Still-Kiss-You-Answering/dp/1558749284

"Mummy's Lump" by Gillian Forrest and Sarah Garson

A children's picture book-style booklet for families wishing to talk to their children specifically about breast cancer. The story follows a mum and son as they learn about the mother's diagnosis and treatment.

Website link: mummys lump 2015 web.pdf

"The Secret C: Straight Talking about Cancer" by Julie Stokes

An illustrated guide for children aged 4-11 to help them approach the realities of a family member having cancer. It primarily deals with validating the emotions of the child with some basic explanations of cancer and its treatment options.

Website link: <u>https://www.amazon.co.uk/Secret-Straight-Talking-About-Cancer/dp/0955953928</u>

"When Someone You Love Has Cancer: A Guide to Help Kids Cope" by Alaric Lewis



Uses child-friendly language and illustrations to explain what cancer is, the terminology surrounding its treatment, and the potential consequences of the illness, as well as the healthy emotional reactions children may have when someone in their life has cancer.

Website link: <u>https://www.amazon.co.uk/When-Someone-You-Love-Cancer/dp/0870293958</u>

"When Someone Has a Very Serious Illness: Children Can Learn to Cope with Loss and Change" by Marge Heegard

An activity book produced by Marge Heegard to help parents teach their children learn the basic concepts of illness and discover various age-appropriate ways of healthy coping with serious illness in the family.

Website link: <u>https://www.amazon.co.uk/When-Someone-Very-Serious-Illness/dp/0962050245</u>

Other APSS Information and Resources

The Adult Psychological Support Service has a range of signposting information sheets on topics such as: coping at different stages of the cancer pathway, supporting your physical and emotional wellbeing, relationships, and information specific to certain types of cancer.

You can view the signposting information sheets on The Royal Marsden's <u>Patient</u> <u>Information Library</u> and the <u>Adult Psychological Support Service Website</u> (under 'Further information and resources'). You can also request a copy of these by emailing <u>Psychological.SupportAdmin@rmh.nhs.uk</u> or telephoning **020** 7808 2777 (Chelsea) / **020 8661 3006** (Sutton).

Additional support services

Cancer Care Map

An online database of cancer support services. You can search by postcode or by particular themes e.g. cancer type.

Website link: https://www.cancercaremap.org/

Maggie's Cancer Centres

Cancer care centres with multiple locations, including The Royal Marsden Hospital, Sutton and Charing Cross Hospital, West London. Workshops, groups, information and one-to-one counselling available.

Website link: https://www.maggies.org/

Phone number: 0300 123 1801

NHS Talking Therapies

NHS website to help you find your local psychological talking therapies service based on your GP address. Your local NHS talking therapies service can be helpful if you would like psychological support for cancer when you are no longer regularly coming in for appointments at The Royal Marsden, as well as for concerns unrelated to cancer or that predated your cancer and have become worse due to it.



Website link: <u>https://www.nhs.uk/service-search/mental-health/find-an-nhs-talking-therapies-service/find-your-gp</u>

If you need any specialist and personalised advice about your cancer treatment, symptoms or side effects, please contact The Royal Marsden Macmillan Hotline. This hotline is available 24 hours a day, seven days a week on **020 8915 6899**.

The Royal Marsden's Adult Psychological Support Service offers short-term, cancer-specific psychological and psychiatric support. You can either self-refer or ask somebody in your Royal Marsden healthcare team to refer you. For more information, visit <u>Adult Psychological</u> <u>Support Service | The Royal Marsden</u>. Alternatively, contact us directly on **020 7808 2777** (Chelsea), **020 8661 3006** (Sutton), or email <u>Psychological.SupportAdmin@rmh.nhs.uk</u>.



If you have ideas for other signposting or information sheets, or if you would like to be involved in working with APSS to improve the service we offer, please scan the QR code to see more about our patient and public involvement, or email <u>Psychological.SupportAdmin@rmh.nhs.uk</u> or telephone **020** 7**808** 2777 (Chelsea) / **020 8661** 3006 (Sutton) with your ideas.

Copyright C 2024 The Royal Marsden NHS Foundation Trust All rights reserved

Published 01 January 2025 Planned review 01 January 2026

