ONCO' ZINE

A Rough Guide to CANCER

By people who have lived it
This zine was produced by the Francis Crick Institute for the Outwitting Cancer Exhibition. It was co-created with members of the Patient Advisory Panel, who have personal experience of cancer as a patient or carer.
WHAT IS CANCER?

Makes you re-evaluate your identity. Cancer is part of me but I'm not defined by cancer.

Losing control

Indiscriminate. Why me? Or why not me?

The brunt of stigma and taboo

A bit Sh*t

Worry

Fear

A sense of reconciliation, value and purpose in life

Side effects of unpleasant treatment - vomiting and fatigue

Town planning gone Mad

Wounds that don't heal - cancer frequently finds ways to hijack treatment

Something to battle/fight

Death
Cancer is an evolving system that plays by evolving rules.

Francesca Ciccarelli, CRICK Scientist.
- Uncontrolled growth of rogue cells.
- Cells in the body misbehaving.
- Cancer is not a foreign agent—mutations are part of you.
- Not one thing—there are over 200 types of cancer and each person’s cancer is unique.
- Multi-causal and involves changes in your genes triggered by carcinogens in the environment; but not necessarily attributed to lifestyle.
- Random and usually unpredictable: It could happen to anyone.
- A consequence of ageing.
- It’s a very natural process (it’s been around since the dinosaurs).
HOPE ON THE HORIZON

- Cancer is increasingly controllable and can be contained.
- More effective drugs and kinder treatments are being developed.
- Quality of life and lifespan for people with cancer is continuing to improve.
- Scientists are continuing to make great strides in cancer research. There is hope!
Research is where hope starts

—Patrick
The Crick houses a diverse and international community of talented scientists all working on improving human health.

Understanding how our bodies work when we’re healthy helps to decipher how to fix it when things go wrong.

Crick researchers are working together to discover new ways to diagnose, treat and prevent cancer.
Over 1300 of the brightest minds working together - a hive of activity - Rachel

It’s amazing that the people working at the CRICK, wearing the white lab coats, are trying to help people like me. - Nevo

Knowing that people are working on and toward changing lives offers hope, promise for the future and invaluable education - Shae

Research is the road to cure - Aisha
Sensationalist headlines can raise false hope, create urban myths and perpetuate fear. There’s a real story behind the headlines but how do you know if you can trust what you’re reading? You often need ‘a sense of tumour’ when reading news headlines about cancer.
As soon as I see the word cancer in a headline I instantly think it’s balls!
Cranberries hailed as breakthrough in battle against killer disease.

Eating just 200 cranberries a day could cut your risk of cancer by up to 22% or more, leading experts said today.

More than 16,000 Brits are struck down by bowel cancer each year.

However, experts now believe that newly discovered cancer-busting properties of cranberries could prevent many of these deaths.

Researchers at the University of Notsosure found that mice fed a diet containing cranberries were less likely to develop pre-cancerous growths, with the levels found to be 22% lower than a control group.

Scientists were unable to discover why there were decreased incidences of cancer in the 12 mice studied but suggested it could be due to “unique supercharged chemicals found in cranberries which have been linked with anticancer properties”.

Dr Rich Farmer said: “The impressive therapeutic benefits of cranberries are just now being revealed.”

Patients could now be prescribed a course of fortified cranberries to supplement their cancer treatment, potentially revolutionising conventional therapy.

“Cranberries aren’t just a great source of essential vitamins and minerals. They’re potentially a miracle fruit.”

Doctors hope that future studies and clinical trials could lead to so-called “crancer therapy” being rolled out to patients in the near future.

By Steve Hatchett-Jobs
CURE - Cancer is not a single disease, there are more than 200 different types of cancer so finding a single cure is unlikely.

BREAKTHROUGH - Terms like breakthrough can lead to false hope.

LEADING EXPERTS - Who are they? Are they credible?

“STRUCK DOWN” - Insensitive and sensationalist language. Beware of claims that quantify risk reduction - up to 22% and more - how can it be less and more than 22%?! How was this figure calculated?

MICE - This study was conducted on mice not in humans, the researchers used a very small sample size of 12. How preliminary is the data? How much more research is needed to substantiate the claims?

SUPERCHARGED CHEMICALS - What does this mean? What are these chemicals and where is the evidence? All foods are made of chemicals anyway.

DR RICH FARMER - Does this person possibly have links to the cranberry production industry? Are they biased? What is the motivation behind the article? Who is funding the research? Is there a conflict of interest?

NEAR FUTURE - Makes it sound like next week, but in research going from experiments in mice to an effective treatment for patients can take many years.

Don't believe everything you hear or read. If in doubt check with your doctor, nurse or another expert in cancer care. - EILEEN.
READING BETWEEN THE LINES:
TOP TIPS FOR DECIPHERING HEADLINES

- **PICK’N’MIX** - Be selective about where you get your information from. Use a variety of sources to gauge if there is a consensus.

- **WHO’S YOUR SOURCE?** - Seek primary evidence for any claims made. Where does the information come from, is your source credible? If it comes from a newspaper or website what is the original source? You can track down the scientific paper to find out more information about the research, the researcher and whether it has been peer reviewed (vetted by other experts in the field).

- **ASK QUESTIONS** - What did the research involve? What are the limitations? Check the sample size, methods and interpretation. For example, a study based on a large number of people, over a long period of time with rigorous controls and a robust method, is probably more reliable than a short-term study with a small sample size. Was the study looking at humans or using animal models?

- **ACCURACY** - How sensitive are these tests and how prone to error? Has the experiment been repeated by someone else and achieved the same results?

- **GO BEYOND THE HEADLINE** - Sometimes the crucial details of the story may be buried in the smaller print.

- **CORRELATION IS NOT THE SAME AS CAUSATION** - There is an important difference - just because two things look related does not mean that one caused the other. There may be other factors at play.

Discover more about the facts behind the headlines at: scienceblog.cancerresearchuk.org and nhs.uk/news/cancer
TELLING PEOPLE
YOU HAVE CANCER
IS EXHAUSTING
It can be daunting starting a conversation with someone with lived experience of cancer. It’s normal to be unsure of what to say or to be afraid of upsetting someone. Here is a short guide on how to start a conversation and to give you more confidence in talking about cancer.

**ASK IF THEY WANT TO TALK**
It is important that the person feels supported and is able to talk when they are ready. They might not be ready just yet... keep trying and keep talking.

**FIND A COMFORTABLE SPACE**
Find a safe place where they feel comfortable talking and make sure that you have plenty of time to listen.

**ACKNOWLEDGE THE NEGATIVES OF IT**
Cancer is pretty sh*t and it’s OK to say so. This can allow the person to tell you how they are feeling...

“When I told my female friends about my mastectomy they all said ‘don’t worry it’s not a big deal’. I told an ex-boyfriend who said ‘oh my god you’re going to lose a tit!’. I felt better once he said this as I wanted people to admit how big a deal it was!”
- Penny AKA ‘One Tit Wonder’

**OFFER HELP (BUT BE SPECIFIC!)**
Rather than saying “Let me know if there’s anything I can do”, why not offer something specific e.g. “Would you like me to cook for you?”/“Do you need some help with the shopping?” They might be more willing to talk to you or tell you what they need. Especially if you tell them what you are good at doing.
DON’T
PRETEND YOU CAN MAKE IT BETTER
- It may push them away.

TELL OTHER PEOPLE’S ANECDOTES
(Unless there really is a useful nugget of practical information to share about the other person’s experience of cancer). You may know someone who has cancer but everyone’s cancer is different which means no one’s experience of cancer is the same.

SAY “YOU LOOK SO WELL”/
“YOU LOOK DREADFUL!”
“Not all cancer patients look like what we typically think of as a cancer patient. People are on different treatments with a variety of side effects, and outward appearances can be deceiving.” — Christine

PREDICT THE FUTURE
You are not Mystic Meg! Unfortunately, cancer is unpredictable and you don’t know what the outcome will be and so it isn’t helpful to try and predict what might happen.

USE PHRASES LIKE “YOU’RE SO BRAVE”
OR “YOU’RE A FIGHTER”
Some people with lived experience of cancer say that these phrases can make them feel guilty that they are not “doing enough” or “trying hard enough”. Instead you can let them know that they are not alone by giving them your support.

“We are urged to ‘stay positive’ and ‘keep fighting.’ But what happens if you find you can’t see your body as your enemy? Whoever I am and will be, cancer did not make me a warrior.” — Tamsin

Talk to me.
Listen to me.
-SHAE
OH MY GOD
YOU'RE GOING TO
LOSE A TIT!

-PENNY
WHEN YOU MEET SOMEONE DURING OR AFTER THEIR TREATMENT

Coming to the end of a treatment round can be an uncertain time. There may be further treatment and tests and a cancer diagnosis may have a long lasting impact. People may feel vulnerable at this time so it might not be time for a big celebration. It’s good to avoid asking questions like “are you in remission?” or using words like “cured”. Instead it is good to check in and ask “what happens next?”

Time is precious. Once a treatment milestone has been reached, why not ask if they want to do something to mark the occasion?

ROOM 101 – WHAT’S THE WORST THING YOU HAVE HEARD?
- “How long have you got?”
- “You look great!” (as if you’re surprised that person isn’t looking dreadful)/“You look terrible” (why do you think they want to hear what you think of their appearance?)
- “My pet hamster/dog/cat just had cancer and it was awful!”

TEXT MESSAGES
If you can’t speak in person to someone do think about the best way of reaching out to show your support through texts and private social media messages. It can be exhausting for the person to keep explaining themselves. Doing it digitally may give them time and space to reply at their own pace.
CANCER RESOURCES AND SUPPORT:

CANCER RESEARCH UK is a cancer research and awareness charity that aims to reduce the number of deaths from cancer. www.cancerresearchuk.org 0808 800 4040

CATS (CANCER AWARENESS IN TEENAGERS AND YOUNG PEOPLE SOCIETY) the CATS campaign aims to educate young people about the common signs and symptoms of cancer. www.thecatscampaign.org 0161 214 7981

MACMILLAN CANCER SUPPORT is one of the largest British charities and provides specialist healthcare, information and financial support to people affected by cancer. www.macmillan.org.uk 0808 808 0000

MARIE CURIE is a charity that provides care and support to people with terminal illnesses and their families. www.mariecurie.org.uk 0800 090 2309

TREKSTOCK (YOUNG ADULT CANCER SUPPORT) aims to help young adults with cancer in the UK to thrive with, through and beyond a diagnosis of cancer. www.trekstock.com
MENTAL HEALTH SUPPORT:

SAMARITANS is a charity aimed at providing emotional support to anyone in emotional distress, struggling to cope or at risk of suicide.
www.samaritans.org
116 123

MIND offers information and advice to people with mental health issues and lobbies government and local authorities on their behalf.
www.mind.org.uk
0300 123 3393

EXHIBITION:

OUTWITTING CANCER
Making sense of Nature’s enigma
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This zine is for everyone, not just those with experience of cancer. We want you to be curious about cancer. We believe that knowledge is power. Keep the conversation going...
Share this zine with someone you know. Have your say:

#OUTWITTINGCANCER

OUTWITTING CANCER
Making sense of Nature’s enigma

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