



My Cancer Navigator

Helping to navigate the minefield

Pan Pantziarka

🧬 LFS UK 2024 🧬

Supporting LFS families, promoting research,
building community

📅 Saturday 14th September, 10:00 - 17:00



Disclosure: I work for the Anticancer Fund as Director of Drug Repurposing

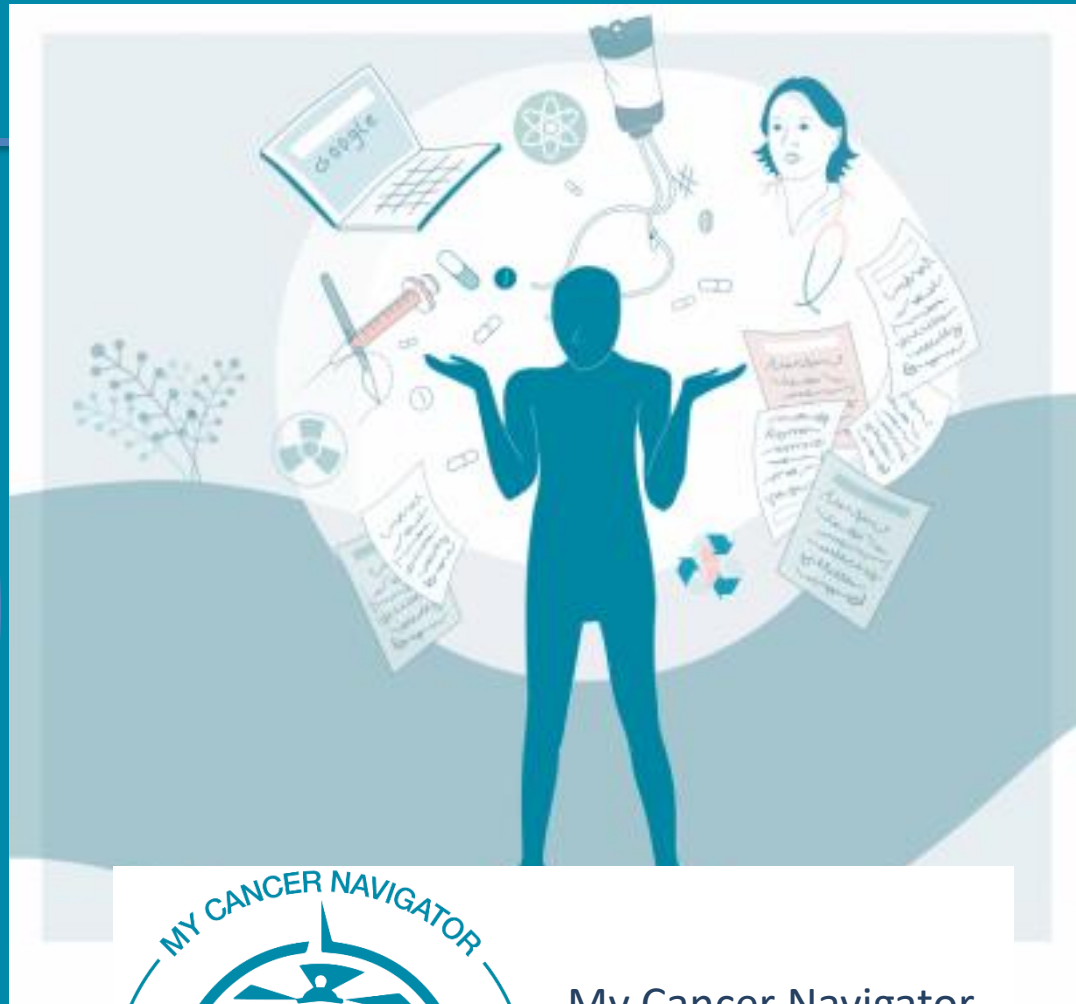




**You or a
loved one is
confronted with
cancer...**

Now what?

bronchoscopy PSA
 blood tests radiotherapist
 gastroscopy PDL-1
 CT-scan EGFR TRUS onco nurse
 anesthesiologist surgeon colonoscopy
 FNA ERCP MRI echo MSI
 oncologist biopsy PET/CT
 bone scan CEA NGS
 HER2 positive LFTs
 K-RAS



My Cancer Navigator (MCN) is a free service designed to help you find *your way*



What does it do?

MCN delivers free, *personalised* and evidence-based *information* in English, Dutch and French on topics such as:

- Treatment options per guidelines
- Clinical trials
- Centres of excellence
- Info on unregulated therapies / private clinics
- Meaning of scientific/clinical information

Questions from:

- Patients
- Parents of children with cancer
- Partners, siblings or friends
- Doctors

The MCN team:

Four GPs – interface directly with patients/users

Four scientists – collecting the data to answer questions

Five specialists (oncologists) – provide clinical input

=> It supports informed and shared decision making, between patients and doctors, as noted in the European Code of Cancer Practice



How does it work?

Always guided by the patient's questions, and without giving advice



Initial contact via

- Phone
- E-mail
- Online contact form

Patient takes well-considered decision together with treating physician



MCN and LFS

- MCN team is very aware of what LFS is (and what it isn't!)
- Many LFS patients have been referred to MCN via the George Pantziarka TP53 Trust
- The focus is very much on cancer-related questions – for non-cancer TP53 questions come to us first!
- Good feedback from LFS patients who have used the service (not all of them from the UK)





User feedback

97%

– **satisfied** with the service

86%

– feel they have more **knowledge**

77%

– have experienced a positive effect on **emotional well-being**

60%

– can better **communicate about treatment preferences** with their treating team

52%

– report a change in **disease management**

Testimonial

STEPHANIE – Sarcoma –
35 years

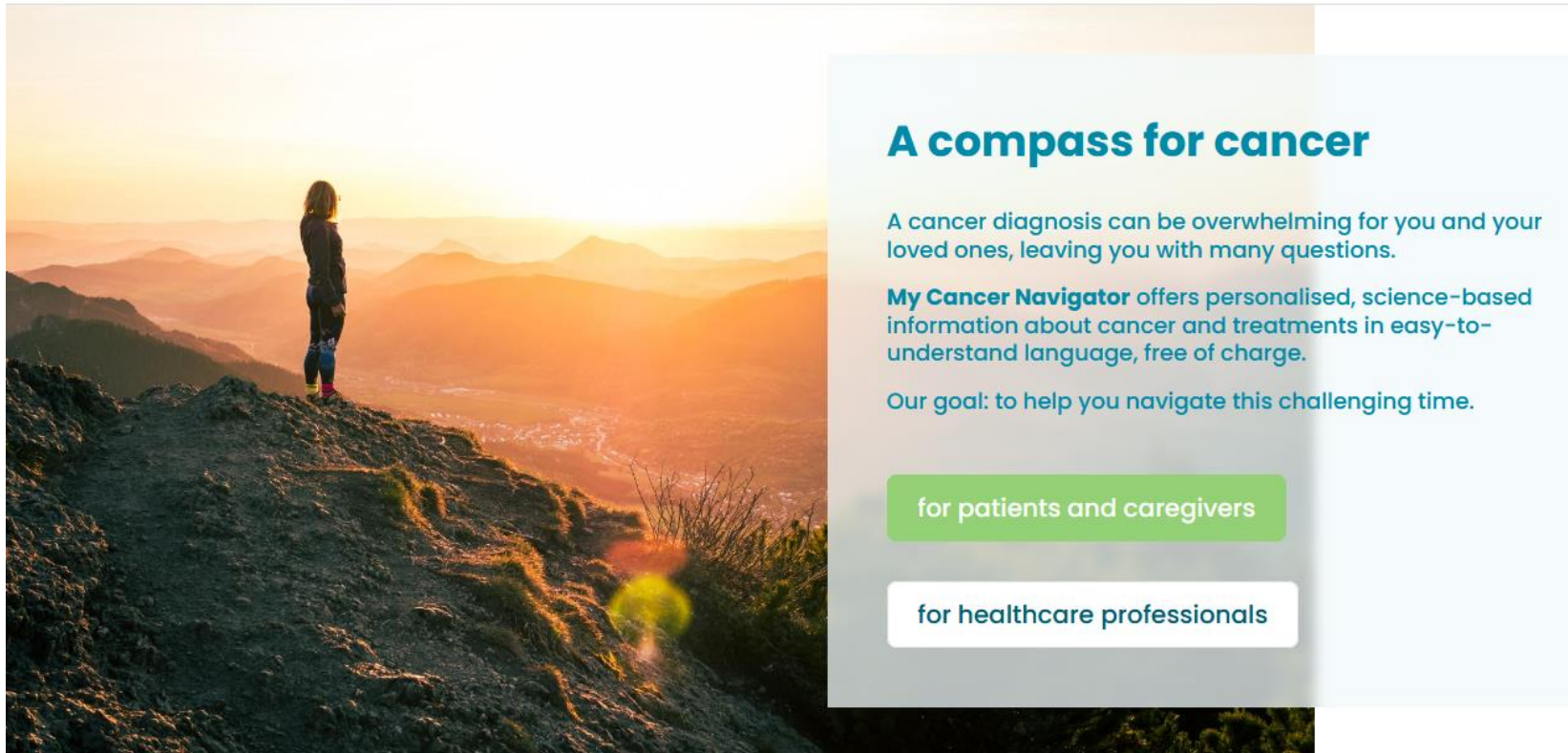
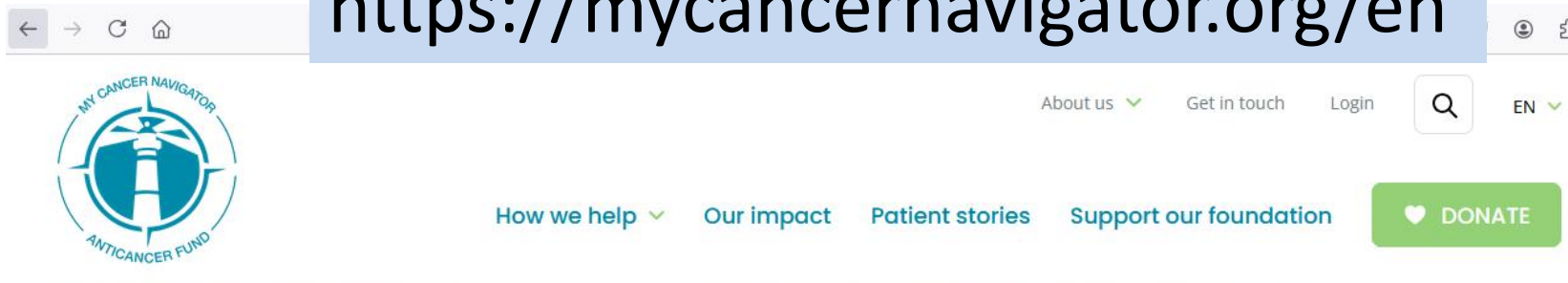


MCN enabled me to see the trees through the woods and acted as a true coach to point me in the right direction on the road to healing. I am extremely grateful for the help I received. It was fantastic to have a reliable point of contact where I could go with my questions.



How to contact MCN

<https://mycancernavigator.org/en>



If you're not sure whether your question is too LFS-related you can always contact us first:

www.tp53.co.uk