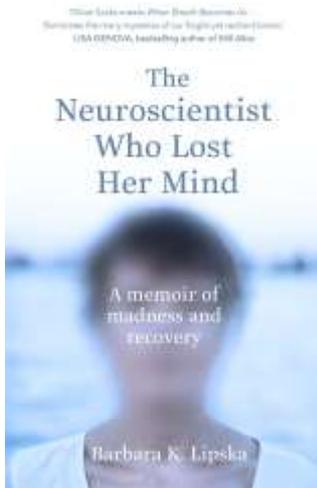


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# BOOK REVIEWS

Read what people affected by cancer think about...



## **The neuroscientist who lost her mind (2018)**

Lipska BK.  
London: Bantam Press, 2018.  
xix, 188pp.  
ISBN 9780593078921.

**Average star rating 4.3 (out of 5)**

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This will be most useful for patients with brain cancer but also for family and friends, particularly if the patient has behavioural problems. It will give some explanation of why and how behaviour may change related to the part of the brain affected. Medical and nursing students would learn much as well. The underlying science is well explained and there is a list of helpful references at the back of the book.

It is written in chronological order and very well presented and printed – the scans are clear. It can be read quickly but can be re-read for deeper understanding. It is very easy to understand, and all medical and scientific words are clearly explained. The book was written with Elaine McArdle but no information about her is given.

It is a compelling story and you don't want to put it down. The changes in behaviour are very well explained. We are given an honest set of different and often distressing behaviour patterns and then the underlying reasons why they may happen. As important is the way they are diagnosed and treated. I like Lipska's honesty and how she related to her family and physicians. All these responses will be comforting to relatives. I also like the detailed science – Lipska is a neuroscientist.

This book will be very useful especially to patients and their family. It is an account of what happened, not how wonderful we were to overcome diagnosis and treatment. By the end of the book you are so pleased she did well.

#### **Retired GP (66-75) (July 2019)**

This illuminating book gives a very clear idea of what it is like to lose rationality and the ability to reason. Anyone could read it and find it useful. Lipska's experience can be useful in everyday demanding situations when someone we meet presents as unreasonable in the extreme. It is particularly useful for the emotional aspects, when struggling with someone whose behaviour is off-the-scale unreasonable and useful as a gauge to the level of difficulty the person with cancer is experiencing.

Lipska, an expert neuroscientist explains everything clearly. It reads as a story in a logical order but if, like me, you don't like animal experiments, start at chapter 2 where she tells us (p. 17) that, "... the brain structure that I sabotaged in thousands of rodents will begin to malfunction, spectacularly, in my own brain" and wonders if "...the rats are exacting their revenge on me".

Lipska experiences sudden visual loss and, owing to her area of expertise, realises that, if this is “not ocular”, something is wrong with her brain. She insists on driving even though she knows she cannot see well enough to drive safely and I felt a sense of rising anger that she shows little, if any, care for the potential risk to other road users; she tells us (p. 27) that, “Somehow, we arrive at the MRI centre without getting into an accident”. She has the luxury of expensive medical insurance and the option of immediate scans and treatment the very next day at the hospital her daughter suggests, although blizzards delay treatment for two days. Still, that is very fast indeed; I cannot help but wonder what happens to those who can’t afford expensive insurance and again I am so grateful for our NHS.

By the time we get to chapter 5, Lipska’s brain is so swollen from treatment and tumours that her behaviour has made her seem obnoxious. On p 77, as a child “...continues to cry, my loathing increases... I hate the little boy. I hate his father. I hate this place.” Her behaviour worsens, distressing her family, although she is unaware that her increasing anger is disproportionate and unreasonable. She has, (p. 80), an “...inability to recognise my own impairment often observed in people with mental disorders.” And has been turned into, “... the worst version of myself” (p. 82).

Lipska’s insistence on driving, even though she is dangerously incapable, is appalling yet, it is this very strength of character that gets her through the horrendous side effects that would have many of us give up. On p. 156 we read of the “...bleeding sores on my hands, lips and face... I look like a vampire after a busy night.”

This is a fascinating insight into mental illness. I’m not sure that it will help people with brain cancer given that the potential for insanity is frightening and might cause distress. It will, however, be useful for carers. It is shockingly illuminating. We read, among other incidents, of how she wet herself while walking, not caring what people thought; when I finished I was wondering how many people we meet in the streets might be suffering from mental illness. Does that person smelling of urine have a mental illness? I notice a man outside the supermarket talking to himself with only two bottles of coke for company and greet him warmly. I take with me from this book an abiding change of attitude: one of more compassion for people with mental illness, and a new way of, I hope, showing I care. For that I am eternally grateful.

### **Caring for someone with prostate cancer (66-75) (April 2019)**

In 2015, neurologist Barbara Lipska discovers that she has metastatic melanoma in her brain. Although she is largely unaware of the changes, it radically alters her personality. One of the most fascinating parts of this book is that it highlights how reliant we are on a stable mind and what can happen when this is disturbed.

It’s a fascinating read in general but could be helpful for someone who has cancer that has spread to the brain and family and friends, as it describes the changes in personality that can occur with this type of cancer and looks at the impact on family, friends, colleagues, medical staff and people she has contact with daily. It briefly discusses vivisection and some people may be concerned by this.

It flows very nicely and is easy to understand. All medical terminology is explained, and there are some useful diagrams. It's extremely well researched and there's a bibliography. The cover is quite silky, nice to hold and read. I like the photos; they really bring home Lipska's experience and made me feel included as a reader.

Lipska is a wonderful writer. She explains what happens to her from her own point of view but also describes how her children and husband react to these changes in a no-holds-barred narrative. The fear and bewilderment they endure is heart breaking at times but matched by Lipska's hopeful and at times utterly oblivious reaction.

This hopeful and happy book shows the strength and love of Lipska's family. I found it hard to put down! Not everyone with this cancer will find it beneficial to read about the potential changes in personality but as a first-hand account of someone who has cancer that has spread to the brain, it could provide a helpful insight.

### **Burkitt lymphoma survivor (46-55) (April 2019)**

Anyone could read this, but it has most relevance to those with experience of mental impairment caused by any cancer. Lipska describes the mental and physical effects of melanoma that has metastasized into the brain. She is a high-functioning individual, physically and mentally, so the descriptions of her deterioration and the impact on family and loved ones are quite alarming. It is frightening and frustrating to read at times; Lipska is adamant that nothing is wrong – not even close family can persuade her of her diminished mental state.

The hardback is a compact size and easy to hold. The typeface is easy to read, and the few black-and-white pictures are clear. The book follows a chronological timeline of Lipska's diagnosis and treatment. There is a lot of information, but it is concise, which makes it accessible. Lipska is a highly qualified scientist, but this is written as a personal story rather than a scientific paper. Her style is direct and economical. This makes it a very easy read and I found difficult to put down. There is no glossary, but Lipska uses clear terms and explains technical details as they arise. The descriptions of the episodes of mania are compelling reading. The notes section details sources referenced in the book and allows for further reading.

This is a deeply personal account of Lipska's life from a young woman to the present day and her diagnosis. The fact that her speciality is studying the brain gives her story a unique perspective – she is acutely aware of the kind of damage going on. It is very interesting to see that although she is highly educated and understands more than most people, she cannot bring herself to view her brain scans to see how well her treatment has or hasn't worked.

Because Lipska is such a high-functioning individual, it's fascinating to read how even those closest to her found it difficult to challenge her erratic behaviour. The cruellest part is that the patient has no idea they are behaving erratically or that anything is wrong. I like the description of being a survivor at the end. I can relate to the idea of the struggle of accepting being a survivor or what being a survivor really means. The conclusion of this chapter is that it is best viewed as, "the satisfaction of another day lived, another day with the people I love".

There is nothing specific I dislike. Lipska is such a high-functioning personality that there is a risk of trying to compare yourself to her standards. Not everyone can complete triathlons or Iron Man competitions or take any physical exercise during treatment. I could barely walk after some treatments and I led an active life before cancer. But there is no feeling of superiority in the book and I find it quite inspiring to read about people that have managed to keep physically active during treatment.

This is not a reference book on the details of how to cope with melanoma. It is an account of how Lipska coped with it. People living with this disease may find it useful to know that they are not alone and how this affects a person's ability to make decisions. It may also help explain why people act the way they do.

### **Living with non-Hodgkin lymphoma (46-55) (April 2019)**

This book is easy to understand, brilliantly written and very deep. It's very informative and I recommend it for someone with a brain tumour, or indeed anyone.

### **Caring for someone with brain cancer (56-65) (March 2019)**

This book is easy to overlook in terms of design, but the blurb, contents pages and first few lines help to convince the reader to keep going. It's an in-depth but personal experience of someone given a death sentence but who has an acute understanding of the mind. This is a unique perspective and it is captivating to read and easy to understand. I like the story-telling style and how it made me feel. Lipska's experience captivated me. Regardless of whether you have experienced brain cancer, this book has the potential to touch you – Lipska's writing is beautiful and heartfelt.

### **Acinic cell carcinoma survivor (36-45) (February 2019)**



This is an honest account of one woman's exhausting experience and lessons about the brain – our most complex organ. Having survived breast cancer, Lipska, a neuroscientist, was diagnosed in 2015 with metastatic melanoma in her frontal lobe. As the cancer progresses and she receives a range of treatments, she experiences changes in behaviour and personality. She becomes critical of her loved ones, emotionally distant and unloving, irritable, angry, confused, and verbally cruel. The growing tumour also affects her numerical and logical reasoning. Despite problems with short-term memory, her writing abilities remain intact; while part of her brain deteriorates, her ability to write increases and she turns to documenting her emotions and experiences as therapy and a means of capturing her vivid recollections before they dim and fade. Through her knowledge of neuroscience, she can identify how her brain changes during treatment. Ironically, whilst she does not have schizophrenia she lives through some of the aspects of a disease she has spent a lifetime studying and trying to understand. She is a determined and feisty woman, and like everything she does, she does with total commitment and so she writes day and night.

Throughout her ordeal, Lipska remains committed to three major areas of her life: family; work; and exercise. The importance of a strong family is a key message throughout the book; as Lipska's personality changes and at times causes hurt and havoc in all their lives, their relentless patience and hope is pivotal to her survival. Lipska remains committed to her work. Whilst she can no longer physically go into the laboratory and office due to a driving ban, she works tirelessly from home, engaging in telephone conferences with colleagues, writing reports and completing admin tasks. During this time of gruelling treatment, she also continues her physical activity regime, running, walking, swimming and cycling. She undergoes a barrage of therapy: radiation and a combination of two immunotherapy drugs and steroids. Gradually, and untypically for someone with this type of brain cancer, she not only survives to tell the tale through this memoir, but also returns to normal functioning.

Lipska is particularly good at describing some of physical and psychological changes that happen when the front lobe of the brain malfunctions. She tackles it in a logical and chronological order, from realising that something isn't right, to diagnosis, treatment, life with diagnosis and treatment to gradual survival. Given that she is a neuroscientist and the language and concepts at times are complex, it is still understandable because she uses explanations alongside technical language. Near the start there is a diagram of the brain with an explanation of different lobes and their function. Lipska is a natural teacher and has an insightful and creative way of explaining complicated matters to the layperson. An excellent example of this is her explanation of long- and short-term memory formation and its purpose (p. 135). I have no medical training but could follow her explanations easily. For example, she outlines different treatment (cyberknife, stereotactic radiosurgery) but with her expert knowledge she can explain this to the reader in a clear and accessible manner.

The title grabs attention, a theme throughout, with quirky chapter titles (e.g. The Vanishing Hand) and, I suspect, a reflection of Lipska's personality. There are notes for anyone wanting to read more deeply about some aspects of brain tumours. There are also some black-and-white photos of Lipska's brain scan, herself and her family.

I may recommend it. As Lipska admits, her condition was unusual. After recovery, she was able to return to her research, resume her gruelling training and compete in a triathlon. Most people with similar cancers rarely survive to describe their ordeal.

### **Friend of someone with non-Hodgkin lymphoma (46-55) (April 2019)**

This is a good source of accurate facts about current and new treatments and how they affect the patient. It has descriptions of symptoms that should be reported to the medical team and includes subtle changes in personality, such as irritability, anger and confusion. It will be useful for someone with cancer that has spread to the brain, partners, family, friends, and health professionals. It is also useful for anyone affected by a non-malignant formation, dementia, mental illness or injury to the brain.

It is a high-quality compact hardback with attractive cover art and good illustrations. It is not in chronological order but makes sense as a story. The typeface is clear, but the font is too small. The chapters are short, and it is easy to understand and well-explained, without being patronising. Lipska uses immediate and descriptive

language such as, “A raisin like a black sheep hidden in a crevice between two hills”. She is a neuroscientist and it seems accurate at the time of writing (there is a list of references). There has since been further research on the production of neurones.<sup>1</sup>

Lipska writes from experience, relating it to herself as an eminent brain researcher, “alpha female”, and triathlete. Her struggle is seen in terms of running a race and striving to stay in control. It is accessible, with a dramatic and moving opening; all is normal, then suddenly... It reads as an adventure novel, a who-done-it. The anatomy of the brain is clearly explained by a scientist who knows her stuff and understands how damage from a tumour can cause confusion, a sense of unreality and loss of control. It can distort how someone sees the world and fundamentally change behaviour, personality and mood. The symptoms can be like mental illness, attracting stigma and affecting relationships. There are touching details about smells, sounds, touch and the colour of the doctor’s earrings, even during crisis. It shows the value of support from family and friends, balancing this with the anxiety of having knowledge that can confirm the worst and the fear and anger that comes with waiting.

I am not comfortable with the description of brain injury as madness and the role of factors other than genetics is underplayed. I would like more discussion of the ethics of animal research in the context of improving data from human studies. Lipska lives in the USA where healthcare is funded mainly by insurance and new treatments are more readily available, but at considerable cost. However, although the financial pressures are different, the story of the physical and emotional impact of diagnosis and treatment is relevant here. It also has interesting information on mental illnesses not directly related to brain tumour or damage, such as depression, schizophrenia, also dementia and ageing.

Lipska’s book combines the clarity of a textbook with a detailed personal journey through multiple malignant brain tumours. It is an intimate story showing how the support of family and friends can be as important as complex treatment and the extraordinary skills of medical teams. I recommend it. It does not underplay the distress and pain of diagnosis and treatment but is also a story of hope.

1. Boldrini, M et al. (2018). Human hippocampal neurogenesis persists throughout aging. *Cell Stem Cell*. 22 (4), 589-599. (Reported in [The Guardian, 5 April 2018](#)).

### **Retired health-care practitioner with experience of cancer and stroke (56-65) (April 2019)**

While this is a useful read for anyone affected by cancer that has spread to the brain, it is probably more beneficial for those seeking to understand the neuroscience behind it, the brain functions affected and what it is like to experience such dramatic changes (even if not evident to the patient). The main aspect highlighted is that any behaviour out of the ordinary (no matter how small or insignificant) could be an indicator of changes in the brain. Lipska’s changes were as dramatic as going for a run with red dye on her head (and ultimately streaming down her face) to losing her bearings on a drive she did most days – a journey that would usually be done on auto-pilot was suddenly interpreted by her brain as an unfamiliar environment.

It is written in a logical order but, given that the melanoma was affecting her brain and mental awareness, it is possible that the order is skewed. However, to all intents and purposes, it is in a logical order. It is an easy read, in part to Lipska's ability to articulate the complexities of the human brain in way that is understandable. For example, when her daughter (an endocrinologist) challenges her over eating a tub of ice cream (sugar combined with steroids can result in hyperglycaemia), Lipska explains that her obsession with eating sugary treats could be a result of the steroids increasing her appetite, or more likely the tumour is damaging the frontal cortex and removing inhibitions. She also gives the example of people with frontotemporal dementia; in some cases, they gain weight rapidly for the same reason.

The cover has a portrait of a figure with detailed shoulders and clavicles, but the face is blurred giving it an ominous appearance – as though something (her mind) is lost. The photos of Lipska's family highlight a distinction between what is perceived – a photo of her and her husband happily enjoying sushi – and what is really happening – Lipska explains that she had just realised that she could not calculate the tip for the bill or do any maths – while the scan photos give us a visual representation of evident changes to brain structure due to tumour development or reduction. Lipska writes with an air of clarity that is surprising given everything she experiences and uses her expertise in the neuroscience field to link symptoms to brain areas.

It is quite useful in that it is a unique combination of neuroscience / psychology facts and information about treatments / trials that were used to help Lipska. I might recommend it – it will depend on the person. My academic background is in neuroscience and psychology, so I like Lipska's in-depth explanations of experienced psychosis and how she highlights that changes (no matter how small) to certain brain structures can have devastating effects. It could be a revealing insight into the possibilities/signs of dealing with such a cancer but the idea of a tumour causing such changes to behaviour and/or mental health could be terrifying to read.

Without wishing to sound clichéd, Lipska is an inspiration; she has had breast cancer and metastatic melanoma AND she is also an accomplished neuroscientist (just the line "internationally recognised leader in brain post-mortem research and animal modelling of schizophrenia" is enough to make you say wow) and a marathon runner/triathlete (double wow). Her approach to her book is, I imagine, her approach to work and life; she is clear, clinical, endearing, resourceful, tenacious, brimming with pride and full of hope. Her book not only made me look at brain cancer differently but also how life can be approached – with drive and determination.

### **Daughter of lung cancer patient (26-35) (January 2019)**

Lipska details the personality and behaviour changes she experienced because of melanoma brain metastases. It will be of interest to anyone who wishes to learn more about the impact of brain cancer on personality and behaviour. Lipska developed schizophrenia and dementia-like symptoms but managed to recover enough mental functioning to reflect on her experience and share her story. She had a range of treatments (surgery, radiotherapy, immunotherapy, targeted therapy), but does not describe them in detail. It is most useful in helping people to understand personality and behavioural changes that can occur when cancer spreads to the brain.

The hazy cover seems to reflect Lipska's brain fog. The text is closely spaced and the font small, which makes it difficult to read. The text is interspersed with black-and-white photos of Lipska and her family, and illustrations and images of the brain. It is remarkable to compare the scans and see how she responded to treatment. It is mostly chronological, with accounts of how she felt and how she and her family dealt with her symptoms. It is an easy read; Lipska, a neuroscientist, communicates her knowledge of the brain in an accessible way. She explains technical terms in the text and provides a list of references at the end. She writes from a personal perspective, making the book appropriate for a wide audience. Her account is descriptive, insightful and compelling and the tone is personal and engaging.

It provides a good insight into the workings of the brain. It helped me to develop an understanding of the personality and behaviour changes that can occur when cancer spreads to the brain. However, it focuses more on Lipska's mental health than on her cancer. She could have shared more details of her diagnoses and treatments.

### **A relative of someone with breast and lung cancer (26-35) (January 2019)**

This is an honest account of a cancer that we hear about but have little idea of its impact on a patient's mental health and how, in turn, how this affects the family. It is written with raw honesty and must have been painful to do but done it has been and all to the good. It is easy to understand, and the more medical aspects are explained well. The cover is clever, but the font inside is too small, and it a strain to read.

One assumes that we, as experts, will always know what we are talking about but, as this book shows, this is not always the case. I cannot imagine what it must have been like to be Lipska or her family – truly terrifying and in hindsight heart breaking. And yet, here she is writing to tell the tale. It is amazing and insightful into how similar the symptoms of brain tumours can be to other brain diseases and how this could make everyone look again at how people with dementia, schizophrenia, Alzheimer's, and other mental health issues are treated and regarded.

It is sobering and thought provoking, but well worth a read. It is a useful insight into the fact that while treatment is gruelling, it can be very successful, and that families can be on the receiving end of much, however unintended.

### **Living with cancer (myelodysplastic syndrome) (46-55) (October 2018)**



Barbara Lipska describes her experiences with mood swings and behaviour changes brought on by the brain tumours and how they affected her brain and details the effect this had on her family. She is clear about how, at the time, she was unaware of these changes and contrasts her experience with that of her family who were extremely concerned at the changes they witnessed in her. It could be useful for partners, carers, friends and family to be able to understand some of the changes

they may witness in the person who has a brain tumour, but I don't think it will be particularly useful for the patients themselves.

The book is a small paperback with an attractive cover. There are a few black-and-white photographs which were useful; seeing pictures of Lipska and her family helped me to visualise them better. The brain scan pictures are difficult to interpret and didn't add anything to the story. The book does contain some technical detail which Lipska describes in the text. There is no glossary.

I really like Lipska's candid description of her behaviour and reactions to what was happening to her, she pulls no punches and describes her bad behaviour with explanations, not excuses. This made the book feel 'human'. I found the descriptions of behaviour and how this related to brain function fascinating, but difficult to relate back to caring for someone with cancer; this is probably because I haven't supported someone with a brain tumour! Although it is quite a short book, in places where Lipska describes getting lost/disorientated, it feels a little bit repetitive; one of these occurrences could have been cut.

Lipska was (from my interpretation) extremely fortunate in being able to take part in a medical trial and to find treatment for her rare strain of melanoma. As a lay person, I'm not sure of the rates of survival for people in a similar situation in the UK. This might therefore set unrealistic expectations of how likely survival would be for someone in a similar situation. Another thing to mention is that she describes in one chapter how she used animal testing as part of her research work for her day job. Those who don't agree with animal testing need to be aware of this in case they are likely to find this upsetting and/or offensive.

There are some useful insights into how brain tumours can affect someone's perception and behaviour, but I wonder if people may get as much information from her original article <https://www.nytimes.com/2016/03/13/opinion/sunday/the-neuroscientist-who-lost-her-mind.html>. If someone with a brain tumour is experiencing the same behaviour changes as Lipska, they are unlikely to find the book useful as they may not be aware of this and may dismiss her explanations and analysis. It might be of help if someone has not yet experienced this, but again, they might get as much information from reading the original article.

### **Carer (46-55) (June 2019)**

This book celebrates Lipska's journey through an illness that she thought would kill her to good health and continuing triathlons. As such, it does not advise nor consider the many and varying difficulties that others may have. Lipska is a Polish scientist, living in America. She has previously had a mastectomy because of breast cancer and has a diagnosis of metastatic melanoma in her brain. In her laboratory, she has induced brain damage in literally thousands of rats. She calls her illness "the rats' revenge" as she is aware of the irony of her manifesting the exact symptoms that she created in her animal subjects.

It is important to note that Lipska accesses treatment in the USA, a very different system from the UK. Her insurance and high status means that she can summon a

large range of experts across the country who give her immediate attention. She also accesses a clinical trial of new immunotherapy drugs and has CyberKnife surgery and MRI scans without any waiting. It is unlikely that a person with similar medical needs in the UK (and most in the USA) would be able to get such treatment, unfortunately. This limits the usefulness of this book. Lipska writes because she admits that she is obsessed with writing. She is also obsessed with exercising, so much so that two days after brain surgery, she is outside, training. She does not believe in resting for recovery. People may feel inadequate by her standards!

The book travels chronologically and is easy to understand if the reader is interested in medical subjects. Lipska does use some jargon, but it is explained. It is a hardback with a tasteful cover design. The font is slightly small for my liking, but it is clear. There are a few black-and-white photos, which bring the text to life. The book's rather unusual tone comes from the fact that most of it is written in the present tense.

What I find most interesting is that Lipska can describe objectively her unreasonable behaviour resulting from brain inflammation due to her tumours and subsequent treatment. I like her frankness and objectivity. She tells of her rudeness, meanness, self-centredness and aggression towards family and other acquaintances – reducing people to tears on occasion – of her cognitive, spatial and visual difficulties – she describes being unable to calculate a bill or find the way home after a run. She also describes incontinence in public, which is brave of her! The good news is that thanks to immunotherapy and CyberKnife surgery, her symptoms are controlled, and her tumours shrink, and along with this, her cognitive, spatial and mood difficulties.

Lipska does not claim that this book is intended to be useful. It is deeply personal in its account of her experiences and would not necessarily resonate helpfully with those of other people. I found it a very interesting read, but I would not recommend it to someone with a similar condition.

**Former health professional. Former carer (66-75) (October 2018)**

# Further information

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We use reviews to help us compile a list of suggested cancer books, the [Macmillan Core Book List](#). Cancer information centres and public libraries can use this list to select appropriate and relevant books for people affected by cancer.

We add reviews to the [Directory of information materials for people affected by cancer](#) so that people affected by cancer can see what others in a similar situation think about a book. You can also see details of all the books reviewed in the [Book reviews listing](#), which also has links to all the reviews.

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If you are a health professional who would like to review books for us, please [email Sue Hawkins](#), Information Materials Researcher, Macmillan Cancer Support.

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If you are looking for support to help you live life with cancer, you may wish to contact one of [Macmillan's cancer information and support services](#). Or you can call the Macmillan Support Line free on **0808 808 00 00** (Mon-Fri 9am–8pm). We have an interpreting service in over 200 languages. Just state, in English, the language you wish to use. If you are deaf or hard of hearing you can use textphone no 0808 808 0121 or Text Relay.

You can also email us using the [website enquiry form](#). Alternatively, [visit our website](#).

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