

# The impact of a cancer diagnosis before 50

When you think about your 20's, 30's and 40's, what comes to mind? Things like progressing in your career, buying a house. starting a family or getting married?

Probably not dealing with a cancer diagnosis.

#### But, increasingly, this is the reality for many people.

Recent statistics show that more people under 50 than ever before are being diagnosed with cancer and, at Maggie's. we see the effects of this every day in our 24 UK centres.

Maggie's is here for every kind of cancer and every kind of story. And right now, more and more people under the age of 50 are coming through the doors of our cancer support centres.

More and more young people and their friends and families have had their worlds turned upside down at a time when they least expected it.

#### We believe their stories should be heard.

We asked young people to share the impact that cancer has had on them. They have shared how it has rippled through their lives affecting their children, their partners, their workplaces, their futures. They have shared their challenges, their words of wisdom to other young people living with cancer, and what they want the world to know.

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THE SAME AGE AS YOU."
Kerry



## What's the big picture?

According to BMJ Oncology, UK cancer rates in 25 to 49-year-olds increased by 24% between 1995 and 2019.\* That's a bigger percentage change than in any other age group.

The second biggest rise in cases was among the under-25's.
Their rate increased by 16%. By comparison, in the over-75's, there was a 10% increase in cancer rates.\*

Although around 9 in 10 cancer cases are still seen in the over 50s, Cancer Research UK says that early-onset cancers are a "growing cause for concern" - Almost 35,000 people aged between 25 and 49 were diagnosed with cancer in 2019.\*\*

Over the last three years, Maggie's has seen an increase in the number of younger people living with cancer accessing expert psychological and practical support.

During the same period, Maggie's has seen a 44% increase\* in people attending our young people's support groups.\*\*\*

In young people aged 16 to 24, on average, we have seen a 28% increase in accessing support every quarter since 2022. \*\*\*\*

"I would like to be planning my career, a family, what my house is going to look like: however, that seems to have all been taken away from me."

Ross, diagnosed with cancer at 31

"I couldn't relate to anyone including friends, peers and even family. I felt so misunderstood and it felt exhausting trying to get people to understand."

Lucy, diagnosed with cancer at 21

"I was diagnosed in March, had surgery in July, had a baby in August, tried and failed to go back to work, had to quit my job by November in the middle of a cost-of-living crisis and felt broken as a person. If it wasn't for the support of Maggie's then the last eight months would have been very different and the outcomes would not have been as positive."

Chris, diagnosed with cancer at 38

## Our centre visitors on navigating life with cancer

Maggie's centre visitors share the impact cancer has had on them, the aspects they have found most challenging, and how they have learnt to adjust.

These are their real stories.

## DAN

#### Diagnosed at 19.

"The hardest part [of being diagnosed with cancer] was life being put on hold when you are just gaining independence and not being as physically able as I once was. Maggie's was a comfortable place that made it easier, meeting young people with similar circumstances."



## TOM

#### Diagnosed at 20.

"I really tried to not let cancer define me, but I failed to recognise that, naturally, with something as big as cancer – your views and morals change. Your direction has to change in life to help yourself heal and grow. I personally found this very hard, as a lot of my friends were thinking of travelling, and I was unable to have this option with all my appointments for the upcoming few years."



## LUCY

#### Diagnosed at 21.

"It was difficult not to compare myself to my peers when it felt like everyone else's lives were moving forward while mine was falling apart - it was hard to look into the future and make plans and be positive when I was dealing with so much uncertainty."



## IMOGEN

#### Diagnosed at 22.

"I was in my second year of university, studying digital music, and everything was normal. I was going out most weekends. I was in a society and learning how to be a DJ. The main thing was I was just having fun.

"We all joked: "imagine if it's cancer". I better start writing my will. We only joked about it because none of us ever thought it could be cancer. My mum said the famous words: "you are too young to get cancer". And I know she regrets that to this day. But everyone thinks cancer happens when you are in your 60s or 70s.

"On the wards, I was the youngest person there by forty or fifty years. I met a lovely nurse named Laura who said, "right I know you're scared but what we're going to do is treat you and then you're going to go on and live your life." I didn't tell her at the time, and I wish I had, because those words meant so much to me. Cancer felt temporary to me after that."

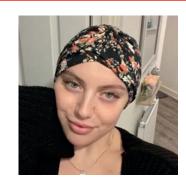


## AURORA

#### Diagnosed at 22.

"I found it hardest not being able to do what everyone else my age was doing. I felt really alone in not being able to go out, go to events, birthday parties, because I was so unwell and unable to move. I felt I had aged 100 years. I learnt to slow down. Life is not a race and just because you have been diagnosed, it does

not mean your life is over. Having cancer will only slightly detour your life path, not change it entirely."



## LIZZI

#### Diagnosed at 27.

"Your experience as a young person is automatically different: your prognosis, the type of life you can lead, your energy levels. But lots of the materials and treatments are geared towards people in their 40's and above. It's hard to work out where you fit.



"After I met two other women of a similar age and with similar diagnoses, my experience significantly improved. I've learnt not to try and manage the emotions and reactions of other people. Sometimes, in the case of being a cancer patient, it's okay to be a little selfish and prioritise your own wellbeing and recovery."

## ELOISE

#### Diagnosed at 28.

"The most challenging part of cancer was feeling like my life plans had changed and things were now out of my control.



"I learnt to listen to my body and know that the experience doesn't define you. There are other people in your position that are your age and you can continue to do things. Life doesn't stop with cancer."

## ROISIN

#### Diagnosed at 29.

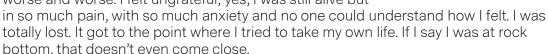
"The most challenging part of having cancer was the lack of control. I have always been a very independent person, moving out of the family home very young, buying my first flat at 25 and living alone for the most part. When I was diagnosed and placed on to the conveyor belt of NHS treatment. I felt I lost a lo

conveyor belt of NHS treatment, I felt I lost a lot of my independence. I like to know specifics – dates, times, etc – but these are never guaranteed."



#### Diagnosed at 30, then again at 39.

"Now treatment was over, all I would hear was, 'You should be so grateful you're still here'. But I became more and more aware that it was getting harder, instead of better. It went on for months and my mental health got worse and worse. I felt ungrateful; yes, I was still alive but



"I struggled with my age; I felt too young for the older people with cancer, but too old to be a young person with cancer and I didn't know how to deal with this happening at my stage of life. I'm not even hopefully halfway through my life, but I was totally out of control and it made me spiral."



## ROSS G

#### Diagnosed at 31.

"The hardest part for me has been the rug being pulled out from under your feet just when you are starting to get your life together and a future mapped out. During my early 30s I would like to be planning my career,



a family, what my future house is going to look like; however, that seems to have all been taken away from me.

"Cry when you need to cry and laugh when you need to laugh. I am someone who finds that humour helps, so if that is the same for you then have fun during the dark times. It's tough. Bloody tough. But take all the help you can from people that know what they are doing. Have your bad days, have your good days, ride the rollercoaster and comfort each other when you are in the depths of despair and celebrate with each other when you are able to."

## **JESS**

### Diagnosed at 34.

"For me, the most difficult part of experiencing cancer at a young age is the impact it has had on my fertility. Cancer has taken away my choice and control over my ability to have children. Something that was supposed to be joyful has become very stressful. I now don't know whether I can have children.



"Nothing takes away the pain of the uncertainty about whether we will be able to have a family, but Maggie's has helped and encouraged me to acknowledge those feelings while continuing to find joy in other parts of my life.

"Support for people with cancer has massively changed as generations go on. My mum was diagnosed with cervical cancer at a similar age to me and I watched her have cancer and then go back to bringing up three children. She said that the emotional and psychological impact of cancer was not really addressed. She just had to get back to life. I feel lucky to have had the support of Maggie's - a safe space that has helped me to discuss and understand some really difficult emotions that I was feeling and know it's okay."

### ZARA

#### Diagnosed at 34.

"My baby was turning one when I was diagnosed with cancer. When you have kids, it adds that extra layer of fear. We had to make sure he was still happy and having fun while we were sorting out cancer.



"Receiving a cancer diagnosis is completely lifechanging but at the same time I was thirty-four years old and had finished treatment and knew I had to go back to work at some point. I couldn't retire at thirty-four. There was no reason for me to not be in work anymore.

"Meeting other people who are in the same boat is so important. Maggie's was the place where I finally met them."

## ASHLEY

#### Diagnosed at 35.

"The burden of cancer is heavy and you're having to carry this along with your biggest fears. My family are amazing, but I would not share this with them as I wanted to protect them and reassure them, even



though I was frightened about what was to come and what my future looked like.

"I have learnt you are never alone when you are dealing with cancer. There are always people you can talk to and relate to. It's okay to feel worried and upset but never feel alone. Cancer is overwhelming and hard to process, take each day as it is and do things at your own pace.

"Dealing with cancer is not easy. It comes with a heavy burden and it is emotionally heavy to carry alone. Please ask for help - cancer should never be faced alone. Reach out and talk to someone. Don't ever feel you have to do this alone.

"Maggie's is everything, a haven of support and kindness, a safe space."

### RACHEL

#### Diagnosed at 35.

"Practically, when I was really struggling with my energy levels following the surgery and during chemo, I adopted an idea that my support nurse suggested where, rather than having a 'To do' list and



getting down about all the things I didn't manage to achieve, I had a 'Ta-da!' list, where I would list everything I'd managed to do at the end of the day and celebrate those things."

"Emotionally, I don't know where I would be had I not found a like-minded group of amazing people through the young adults' support group at Maggie's. Everyone there just 'gets it' and can relate to what you're going through."

## KARL & SOPHIE

Karl's partner Sophie was diagnosed at 36 and died when she was 39 years old.

Karl shares his experience being the partner of someone with cancer and how this impacted him as a person and a parent.



"The endless appointments and trying to maintain a life around that while also raising two small children. Going to work and pretending you're a normal person. Putting much of your life on hold to 'do cancer', but at the same time trying to find moments of life and joy among it all. Putting all your faith in the medical professionals, never imagining that it won't all work, and then having to deal with the fact that it will ultimately fail. Moving into the future as a single parent to two small children who barely had any time at all with the most important and incredible person I ever could have wished to have fallen in love with and to be loved by in return."

## ROSS A

#### Diagnosed at 37.

"The minute you hear the word "cancer", you put a timeline on your expected lifespan. So now, I'm in my 30's and instead of my mortality being miles away, it's all just got a lot closer. How do you react? Do you change your career if you can keep working, and what about your family? Will they be ok? How do you tell your family



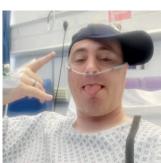
and friends? Do I tell my young daughter? Am I going to ruin my loved ones' lives? All of that weighs on you. I've been very intentional in trying to say yes to things that make memories. I want my family's memories of me being one of me smiling and being there in the moment."

## CHRIS

#### Diagnosed at 38.

"The hardest part for me was the side effects from treatment. This impacted my whole life. Not knowing how unwell I would be, not being able to work, staying in bed while listening to my wife struggle with the children, having to explain to my children 'why Daddy can't play today', feeling exhausted, frustrated due to the limitations it imposes, and not being able to find any routine.





### HANNAH

#### Diagnosed at 38.

"My feeling of fear was off the charts during the early stages of diagnosis. I was terrified that I was going to die young. Other challenges were the 'pickling of my brain' – I craved normality, yet there I was in appointments about having my breast removed, possible IVF, medication that would cause early menopause. I felt like I was on one of those awful rides in a theme park, desperate to



get off. I distinctly remember telling my family and friends that, even though they were 'with me', I felt incredibly lonely in my head.

"The young people at Maggie's and support around me have brought me 'back' now. I'm changed for good, but am largely back to me – as much as possible."

## KEITH

#### Diagnosed at 40.

"The most challenging part of having cancer was the impact on my mental health. When I was first diagnosed with cancer it felt surreal. As treatment went on the pain increased. I started not being able to swallow, was experiencing rapid weight loss, trauma in my past started triggering my mental



health. The more my body deteriorated, the more my mind went into overdrive. I reached a point where I could no longer function and took myself to A&E because I was ready to end it.

"While I was sat in A&E, my friend, who also had cancer, messaged me and said, 'Take yourself to Maggie's. There are people there who will understand what you are going through.' The next day that is what I did. I walked into Maggie's, sat down with Jen and unloaded everything. I knew nothing about Maggie's and they changed my life. Without Maggie's, I wouldn't be here today.

"Art therapy was the best thing I have ever done. We sat there and spoke for the full hour. I was concentrating on what I was drawing and didn't notice I was opening up about everything. I was able to break down and understand where the anger and pain was coming from. Jen calling me back changed my life. From the first day I came to Maggie's, I went back every week. Maggie's is a lifesaver. I don't think I would be here today without them. I was struggling with both the physical and mental pain of being diagnosed with cancer."

## GEMMA

#### Diagnosed at 42.

"The hardest thing to comprehend was not watching my children grow up or ever becoming a wife. I've recently got married so I ticked one of my worries off the list. I found it incredibly difficult to hear the words 'You've got this, Gem', when ultimately this has never been my fight, it's been cancer vs medicine.



"Cancer is the rollercoaster ride nobody wants or should ever have to get on. When the highs occur, embrace them, and when the lows hit, reach out to whoever you need to at that difficult time. Maggie's was my sanctuary, a breath of fresh air in a new world of uncertainty. You are not alone, remember that."

## CAT

#### Diagnosed at 42.

"The most challenging part was juggling life with a young family and managing the emotional rollercoaster of diagnosis and treatment. I was diagnosed when my youngest daughter was just under one year



old. I was gearing up to return to work. I'd moved to be closer to family just the year before and had made some great friends on maternity leave. I was excited about the new chapter ahead. Then I found a small lump in my left breast.

"Everyone kept saying, but you're one of the healthiest people I know. I quickly realised there were lots of misconceptions about what having cancer looked like and meant, so I set up an Instagram account to connect with others going through treatment at the same stage of life. It also turned out to be a great way to share information, resources and my musings about life as a younger person with cancer.

"I remember being at my eldest's daughter's first nativity wondering how many school plays I might get the chance to see. Being faced with contemplating my mortality at a younger age continues to be a challenge. I try to live life to the full, but cancer is like a shadow once you've had it. Sometimes in front of you and easy to see, other times behind you but still following you about, ready to pop up when you least expect it."

## SALLY

#### Diagnosed at 42.

"Because I'm young, I hear people saying I'm too young to have cancer and assuming because I'm young that I'll bounce back. I had made the assumption of decades of life ahead of me, highlighted as potentially wrong.



"The most challenging thing, for me, regardless of my age, is experiencing chemo and radiotherapy, seeing the effects on my body and willingly going to the next session when I really don't want to."

## EMMA

#### Diagnosed at 44.

"I felt complete shock at being diagnosed, with extremely limited knowledge or understanding of cancer. I was diagnosed with breast cancer at 44 and kept being told by the professionals that I was young.



"It has been a roller coaster of a journey, traumatic and has completely changed my life and the life of me and my husband. It is the first time in my life I have had the control taken away from me and not been able to do things I have wanted to. I have had times when I have been extremely upset and not been feeling me, not looking like me, not acting like me and desperate to want to get back to normal but then learning I would not be the person I was before.

"I do not feel that I would be in the good place that I am now without the support of Maggie's. They say 'just come in' and that is exactly how they make you feel, that you can just go in."

## BEN

#### Diagnosed at 47.

"I think I stopped being young a long time ago but my diagnosis meant positive future family things that might happen in the future evaporated, virtually overnight. That was a blow which was hard to live with but once I'd recognised it, life became simpler and easier.



"Therapy at Maggie's helped me find ways to get through the sketchy bits. I've found that this starts with listening to what your mind and body are doing. I've learnt to say no. I'm always trying to be active and keep up with family life, but sometimes declining an offer is the only option.

"Stop making cancer into a fight or a battle. Just living with cancer can be challenging enough. I've lost count of the times that I've woken up with no fight left. I've had to think I'm breathing, that's enough countless times."

## What would you like other young people with cancer to know?

"Sometimes, I would just be upset or angry because I had all these feelings and I did not know where to put them. But you learn to live with cancer and that although you will be a different or stronger person than pre-diagnosis, you are not defined by a diagnosis. You can still be healthy, fun, attractive, interesting, normal."

Tom

"Cancer is the rollercoaster ride nobody wants or should ever have to get on. When the highs occur embrace them, and when the lows hit reach out to whoever you need to at that difficult time. You are not alone, remember that."

Gemma

"You may not be able to do exactly what you were doing before, but anything you do now is an achievement."

Aurora

"I was the person supporting others and always very independent so I have had to learn to ask for help and accept help from others."

Emma

"Find your escape – find something that you can positively absorb yourself into that is not cancer related or find your cancer tribe who understand & you don't have to mask in front of."

Sally

"Don't look things up online - it only makes things worse! Have your bad days, have your good days, ride the rollercoaster and comfort each other when you are in the depths of despair and celebrate with each other when you are able to."

Ross G

"If you have a gut feeling, you must go with it. You must advocate for yourself, even though this can be awkward and hard. Don't back down if you feel something is wrong."

Hannah

"Be strong. Share your journey."

Eirian

"You owe no one anything when you're dealing with cancer, terminal illness, grief and beyond. You find out who you can really count on and equally you learn how to offer better support to others in the future when you can."

Karl

"Cancer is a personal experience and it's your choice on how you want to handle it. You can tell everyone or no one. You have to make sure you do what feels right for you."

Imogen

"I've been very intentional in trying to say yes to things that make memories. I want my family's memories of me being one of me smiling and being there in the moment."

Ross A

"Emotionally, I don't know where I would be had I not found a like-minded group of amazing people through the Young Adults' support group at Maggie's. Even though we're all at different stages of treatment and beyond, for a whole range of cancer diagnoses, everyone there just 'gets it' and can relate to what you're going through."

Rachel

"Help others to support you. To do that you need to communicate. Those around you, even your nearest and dearest, have good intentions but they need direction on how to support you. They are definitely not mind-readers! Be clear about what you need, want, would appreciate and that those things may change day-to-day."

Lizzi

"Make plans. Remember you are a person first and foremost, so don't lose sight of what makes you happy. It's easy to be absorbed by the diagnosis but by taking time to enjoy things, no matter how small, will help when times are difficult. When the times are hard, find an outlet that is a safe space for you. Make sure you have your own space to process your way."

Claire

## What can everyone do to support young people with cancer?

"I wish that other people would treat young people with cancer and their families, the same as they would to somebody without cancer."

Dan

"Ironically, having cancer at the beginning of my twenties really helped me learn a lot of hard life lessons early that I am very grateful for. If I hadn't had my cancer, there is no way I would have reached out to someone for emotional support. There is a large stigma for young men's mental health, and I feel so grateful that cancer has shown me how important and useful reaching out can be."

"Stop making cancer into a "fight" or a "battle". Just living with cancer can be challenging enough. I've lost count of the times that I've woken up with no fight left. I've had to think "I'm breathing, that's enough" countless times."

Ben

"I am incredibly privileged. I recognise I am alive today partly as a result of my skin colour, gender, socio-economic background and where I live. I want the world to ensure equitable access to treatment for people with cancer, their partners and families."

Cat

"It's okay not to feel okay about having cancer. Use resources like Maggie's as it makes you feel like you are not alone."

Kerry

"People's mental health takes an absolute battering when dealing with cancer and needs to be treated as vigorously as tumours. Let's all talk about it. You can't upset me more than I already am, nor stress me out: I'm already thinking about it all the time! I'll appreciate your willingness to listen, and if I don't want to talk about it, I'll let you know."

"I would want the world to be more accepting and realise the life long affects that a cancer diagnosis can have." "I felt guilty for a long time, and it was so important that I had others to talk to who understood why I was feeling that way. And to remember there is life with and after cancer." Imogen

"Support people to continue with their lives."
Eloise

"Many people expected me to be all good again as soon as chemotherapy finished but so much of the recovery and healing still remained. This was when I needed someone the most. Aftercare should be prioritised as well as the treatment itself."

Roisin

"Remove cancer as a taboo subject in society."
Ross G

"Empowering people to manage their life as cancers and treatments are so varied one size does not fit all. When I was first diagnosed I just wanted support that was up-lifting. As my cancer journey progressed I was looking for help on how to do specific things and make improvements to life. Cancer is not a straight forward journey, so cancer support needs to be adaptive to help people evolve with their needs."

Claire

Chris

"Dealing with cancer is not easy. It comes with a heavy burden and it is emotionally heavy to carry alone. Cancer should never be faced alone." Ashley

"The NHS focuses on the physical elements but cancer impacts every element of your life. There isn't much support that tells you how to be a dad with cancer, a husband with cancer or how to maintain emotional and mental health during the process. If it wasn't for the support of Maggie's then the last 8 months would have been very different and the outcomes would have not been as positive."

Lucy

## About Maggie's

- Maggie's has nearly 28 years of experience providing free cancer support and information in centres across the UK.
- Built in the grounds of NHS cancer hospitals, the centres are warm and welcoming spaces run by expert staff who help people live well with cancer.
- In 2023 we had more than 310,000 visits\* to our centres, 45,000 were visits from new people with cancer. Nearly 35,000 were visits from people newly caring for someone with cancer.
- The first centre opened in Edinburgh in 1996.
   Maggie's now has 24 centres in the UK and a growing international network.
- The majority of Maggie's funding is from voluntary donations.

- Maggie's President is Her Majesty The Queen.
- Maggie's Chairman is Stuart Gulliver.
- Maggie's Chief Executive, Laura Lee was awarded a damehood in 2019 for her services to people with cancer.
- "Every cancer hospital needs a Maggie's" this statement has been endorsed by 24 CEOs of NHS hospital trusts where there is a Maggie's.
- For more information visit maggies.org

\*Visits refers to support facilitated by our programme staff and includes face to face; on the phone and online



## Citations

- \* Jianhui Zhao, Liying Xu, Jing Sun, Mingyang Song, Lijuan Wang, Shuai Yuan, Yingshuang Zhu, Zhengwei Wan, Susanna Larsson, Konstantinos Tsilidis, Malcolm Dunlop, Harry Campbell, Igor Rudan, Peige Song, Evropi Theodoratou, Kefeng Ding, Xue Li Global trends in incidence, death, burden and risk factors of early-onset cancer from 1990 to 2019: BMJ Oncology 2023;2:e000049.
- \*\* https://news.cancerresearchuk.org/2024/06/03/cancer-rates-rising-in-under-50s-early-onset-24-percent-increase/#:~:text=Around%209%20in%2010%20cancer,day%20between%202017%20and%202019.
- \*\*\* Data taken from Maggie's programme database, and based on the number of people attending our young people's support groups online and in our centres. Comparison has been made between attendance figures of Q1 and Q2 of 2022 and 2024.
- \*\*\*\* Data taken from Maggie's programme database, and based on the number of people aged 16-24 accessing support online and in our centres. Comparison has been made between Q1 and Q4 of 2022 and 2023, and between Q1 and Q3 of 2024 with the expected projection for Q4 of 2024.