



Walking a mile in our shoes:

Tips from Lucy, a brain tumour
patient's caregiver

If I got paid a penny for every time I was asked

‘are you both OK?’

and I answered

‘yeah we’re fine’

I’d be a millionaire by now. But then there is only so long that you can expect people to ask that, knowing that you’re giving them a fake response and that you’re saying what you think they want to hear. It’s pretty obvious we’re not OK but, putting on a good show of trying to be.

It feels pretty uncomfortable knowing that you’re the people everyone talks about but not necessarily the people that everyone talks to. Kind of makes you uncomfortable in your own skin. Nothing fits anymore, including you - you feel you don’t fit your own shell. We often felt we were Mr and Mrs Invisible. People couldn’t see the new us, only knew how to be comfortable with the original us, not the new 2.0 versions post diagnosis.

You know people want to help but that they are scared to open that door, not knowing what they’ll find or what’s involved. It’s not a judgement, everyone has their own pre-conceived ideas. I know we did!

Based on our experience, here are some things that might help the people you love feel less invisible:

It's OK to talk to us about our trips to the hospital for appointments and to ask us questions.

Whereas life used to just revolve around what time our favourite TV shows were on and what time we were out down the pub, we've had to create some extra time in the schedule for the hospital visits. That's just it, they are an every day part of our lives. We've acquired a whole new dictionary of medical words and terms. We talk about it at home and sometimes would like to talk to a fresh ear about it. Rest assured we will tell you if we don't! If that's the case, don't feel you can't ask again. It's become our new normal. It might brighten our day just knowing someone was brave enough to ask.

We won't be offended if you offer to help around the house (or even sneak round and cut the grass whilst we're out).

All things medical can be exhausting. Hasn't everyone wished at some point that a fairy godmother could pop round and magically tidy up? That doesn't change just because you might be spending more time at home, managing your diagnosis. If anything that wish increases! The more time you spend at home, the more mess you can make. Popping round with a dinner that just needs to be put in the oven will give someone that precious extra time to go out for walk, chat on the telephone or just put their feet up in front of the TV guilt free, what a gift!

Offer to drive us to the hospital - and it's OK to ask more than once!

All hospitals have more patients than parking spaces, simples. Whilst we love to keep our independence, it can be beyond stressful trying to find that much sought after parking space near the entrance. Offer to drop us off and pick us up when we're ready. Hospital appointments done VIP style.

Buy us a Dictaphone.

I wish that someone had suggested a Dictaphone for hospital appointments sooner. Often you don't want a whole crowd of people with you. It can be overwhelming for the person with the diagnosis and depending on the person, it may stop them asking questions. Doesn't mean they don't appreciate your involvement though. A Dictaphone means you can clarify things in your own mind in your own time and play it to family members who might want to hear.

Also - a gem of a gift for someone who may be having memory troubles!

Buy us a medicine dispenser.

I remember having to clear out a drawer in the kitchen to hold medicines and the entire bump the hospital gives you. If only we'd found a medicine dispenser sooner. They're not expensive but allow the patient to split their medicine into what they need to take each morning, lunch or evening for the week. It's a way to take control and to clear the mind of having to worry about remembering. Again a gem of a gift for someone with memory troubles whose world has been turned upside down. Plus everyone likes presents, whatever the shape, size or purpose!

Support us with any diet/lifestyle changes.

We decided to make some major changes to our diet and from what I hear many others do also. It might not just be a conscious decision, it could be dedicated by medicine. However, if it is a conscious decision like ours was, it's a way for us to take control in a new life where we don't have much anymore. Therefore join in and get involved! We decided to reduce sugar intake significantly and my heart would sink every time we were offered a bit of cake as a treat. Remember our thoughts have clarified and there are many more treats to be had than food, such as a hug, a walk in the sunshine or just a good giggle with a friend.

It's OK for us to laugh and it's even better if you laugh with us.

The looks we would get when found laughing, particularly a proper side splitting laugh. I know people found it hard to understand how you could be laughing in such extreme circumstances but life doesn't stop and isn't a good old laugh good for the soul?

Don't ignore the diagnosis.

I would often think to myself 'we can't ignore this, so why should you?' I found it really hard to swallow that people could swan into my fiancé's day and enjoy normal, non-medical conversations with him and leave me with all the difficult ones. We can't pretend the tumour's not there so it's kind of odd when others do.

Don't judge if the patient chooses to work.

You can bet your bottom dollar that it wouldn't have been an easy decision but it's their choice and their entitlement to work if they want to. When they've been robbed of many other things shouldn't they have the satisfaction and achievement of working if they want to? Their awareness of their own capabilities has been highlighted a million per cent by their diagnosis, they'll know if it's time to stop.

How do you get around in today's world when you've lost your driving licence?

The patient could have, at least temporarily, lost their driving licence. Post diagnosis, public transport is probably a scary option. Loud noises can be harder to handle and patients may also carry the worry of people judging them particularly if they have a visible scar postsurgery. Crowded places were just too overwhelming for my fiancé.

Whilst the patient's world has probably shrunk to their home, nobody likes to ask for lifts constantly. Therefore don't wait to be asked, offer by dropping in saying you're just popping up to the shops and would they like to come too. Be creative in how you do it!

Don't offer to babysit but do offer to spend time with each of us individually.

As a fiancé, friend, caregiver, spouse, relative or neighbour, whatever your role as the key person for the patient, you are there for that person out of love. It's not a chore; it's an honour and a privilege and therefore I don't feel I need time off from it. We're a unit in this but we are individuals too and do need time apart to be our own person. Find things to do to spend time with each of us on our own, quality time doing the things we loved before the diagnosis - chances are we love them even more now!

If in doubt, just ask don't assume.

If you want to help but you are just not sure, then just ask.
We're still the people we were before the diagnosis, often just very tired, lost and scared versions of ourselves feeling like rabbits caught in headlights.

**In tribute to the wonderfully brave
and forever young Ryan.**

All that met Ryan were touched by his kindness, quiet determination, spirit and sense of humour (which was often an acquired taste!). Ryan will always be my guiding light and I hope that through this leaflet he can be yours too. Together we can't be alone.

Lucy, Ryan's fiancée.

To find out more about *brainstrust*
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