What carers wish we knew ....

This is the 16th blog by Rebecca Lloyd of the Irish Hospice Foundation (IHF) in the series on The People’s Charter on Dying, Death and Bereavement in Ireland. This month, the theme is around this line of the People’s Charter:

*I and the people who care for me can get the practical services and support we need*

Last week, our blog looked at #celebratenurses and investigated how nurses go above and beyond the call of duty to look after and care for us. In truth, when it comes to thinking about caring for ourselves and others, we tend to look to the medical professionals. While it is of course one of the places we should look for help, there is so much we can do for ourselves and for each other.

And in the spirit of how we can help ourselves and help others, this week we thought we would look at one of the largest groups of people on the front line of care and illness - family carers,— what is it that they wish we knew?

Let’s start with the facts, The 2016 census showed a total of 195,263 persons (4.1% of the population) were providing unpaid assistance on the island of Ireland - an increase of 8,151 (4.4%) on the 2011 figure of 187,112. Women made up just over 6 in 10 carers (60.5%,
118,151 carers) with 77,112 (39.5%) men. There were 3,800 children under 15 years engaged in providing care to others, accounting for 1.9 percent of all carers. (CSO 2016)

That’s a lot of people. We probably work with them, live near them, salute them when we see them, but are we able to help them? More importantly, if we do want to help them, do we know what to do? Following conversations with carers, we have put together some information that you might find helpful.

I interviewed six carers that I know. What they had to say was interesting, they couldn’t really tie what they wanted/needed to one thing, but some recurring stories popped up.

The first tip they had is to keep in contact. Most carers do want to stay in touch, but often they are tired or busy, and life most definitely gets in their way. This can make it challenging for them to manage everyone and everything, so it’s a good idea to perhaps schedule calls. Suggest times, just after lunch or early evening, whenever suits their schedule.

And if you call them, ask them how they are doing and let them tell you. Part of being good support is being a good listener, sometimes that is all that is needed. They might just want to tell you about their day.

One carer who is looking after her elderly mother did say to me
“I want to hear about the world, I want to hear the gossip, what happened at the weekend, who was there and what they did. I don’t just want to talk about Mum’s ailments I want to feel I am still part of everything and knowing a bit of the gossip is a great way to be always included.”

Another one said,
“I hate asking for help. I just wish people would just do something rather than leave me with ‘If there is anything you need let me know’. That means I have to get to the point of needing something, remember who said that to me and then contact them. I rarely have the headspace to do that, so I just end up doing it all myself. I just wish sometimes people would
just do it. Like mow the lawn, or get the basics from the shop. A little text that they are going somewhere do I need anything? That would do.

One day my neighbour brought round ‘sushi’ of all things. Me and mum roared with laughter we had never tried it before. But we did that night, and it was lovely. It is so difficult to think about what I want, and I would never, ever have said sushi – but in the end that was exactly what we wanted and needed. It was great!"

A lady in her sixties who is looking after her friend spoke about her tiredness;

“I am exhausted all the time,” she said, “and I try to remain upbeat for my friend but sometimes it is just so tricky. I become grumpy and irrational. It is these times that I would love people to step in and just give me an hour off. What I would do for a massage, or to get my hair done, my nails done – it would be lovely. So if I wish my friends knew that and could come in and take my place once in a while, it would be a dream come true”.

A man who is caring for his wife only had one point to add;

‘There’s not much I need’ he said, “we do get along really, we’re okay. I just hope that people will keep calling me, keep asking me out, even when I say no all the time and when I am distracted. Please keep calling. Just knowing you care is enough and wanting to spend time with me is a great solace.”

In addition to the voices of the carers there is also a lot of generic advice - the advice that is on the websites and the leaflets. Sometimes this information might not get to the people that need it because they are too busy to look for it.

This provides another opportunity for us to help. If there is a new support group opening somewhere and you see it advertised, note it down. Are your carer friends getting everything they are eligible for? Perhaps you could do a bit of research for them? Maybe that is how you can help. Print it out and highlight the relevant bits. They might not take everything up immediately, but there might be something that will help.
So whether its common sense or a desire to help we hope these little tips might help you reach out to someone. By merely offering real help we can make a difference in the life of a carer and in turn to the person they are minding.

Remind them that you care, and they matter.

We can all add to the supports people need no matter how small. And although most of this article is common sense it is no harm to remind ourselves once in a while that as my mother used to say "it is nice to be nice."

For more information of volunteering for the Irish Hospice Foundation go here.

If you are a carer, our website is brimming with information that can help you and your loved one.
You can read more about The People’s Charter on Dying, Death in Ireland here

The Irish Hospice Foundation is the only charity dedicated to dying, death and bereavement in Ireland. 80 people die in Ireland every day and the IHF believes everyone has the right to be cared for and to die with dignity and respect in the care setting of their choice. Our mission is to strive for the best end-of-life and bereavement care, for all. The IHF campaigns to make excellence in hospice practices, bereavement and end-of-life care a national priority and to stimulate the conversation about dying, death and bereavement in Ireland. Full details: www.hospicefoundation.ie