

Foreword: Margaret Kitching

Hello!

My name is Margaret Kitching and thank you for giving me the opportunity to write this foreword.

I am a nurse and while my current role means that I am no longer hands on with patients on a daily basis, I still use the guiding principle of including family carers and relatives in whatever I do.

Like most of you reading this, I have many other roles, including being a mum and an auntie to an adult niece who has a severe learning disability and autism. I bring my experience of both these roles to my day-to-day work. The importance of a family carer must never be underestimated and advocating on behalf or alongside their relative regardless of whether it is as a parent, sibling, or other relationship, is so important.

Family carers are in a unique position, they have been there for their loved one's entire journey. Their input may have led to a diagnosis being sought and they will have been there for every part of their journey, for example, securing appropriate education, a successful transition from children to adult's services and to accessing the right support to ensure an ordinary life for their relative in the community. Family carers have invaluable knowledge such as their relative's individual way of communicating, what a particular behaviour means, and how their relative responds when they are unwell – physically or mentally.

This is recognised in law, for example if a person with a learning disability, autism or both needs somebody to advocate on their behalf they have

a statutory entitlement to an Independent Mental Capacity Advocate only if there is no family member or friend available. Despite this, family carers still find themselves fighting to be involved as equal partners in their relative's care – it is therefore so important that family carers are provided with information about their rights, and the rights of their relatives.

I have personally been involved in Rosemary and her son's journey. Although there have been challenges along the way, never once has Rosemary's commitment waived. Her strength and tenacity helped to drive her son's discharge from a mental health service back to an ordinary life in his community.

What struck me with this specific case is how Rosemary had to independently learn about her rights as a family carer and those of her son. Often, the information came from other family carers and very rarely from the health and social care professionals supporting her and her son.

We must ensure that family carers have access to the right information at the right time in a way that is accessible. I hope that by bringing together the relevant information in this resource, family carers will be able to access information about their rights and those of their relative.

I never underestimate the challenge of being a family carer; the lifelong fight to achieve what is best for your relative. I hope this resource goes some way to giving family carers the information and confidence to support you when advocating for your loved one.