

Emotional Wellbeing in Parents of Disabled Children

Notes to accompany the Rescare forum on 24th November 2021 by Zoom

Introduction

Dr Joanna Griffin is a parent carer (her son is 14 and has cerebral palsy, learning disability and autism) and Counselling Psychologist who has been researching emotional wellbeing in parents of disabled children.

Joanna's research (and personal experience) informs her book *Day by Day: Emotional Wellbeing in Parents of Disabled Children* which is available here: www.amzn.to/3k1NReK

Parenting a disabled child can elicit complex emotional responses. For many parents, the focus of those around them is solely on the child and their own needs become neglected. By sharing our experiences, we realise that there are many commonalities. Joanna explores what helps, and hinders, parent carers' wellbeing.

The website www.affinityhub.uk signposts to emotional support for parents of disabled children, including organisations and private counsellors. As well as outlining common emotions and wellbeing tips there are quotes from parent carers on the impact of parenting and advice to others. Hearing from other parent carers can help us realise that we are not alone.

Why is your wellbeing important?

Often, as parent carers, the focus of those around us is solely on our child and we may get stuck in a 'carer mentality' where we feel selfish for focusing on our own needs or taking time for ourselves. This is not helpful and can lead to [burnout](#).

The messages we get from the media and tv about how parents/carers 'should' behave as well as how families 'should' be are partly to blame. This is not reality and family life can be far more complex than this.

The effect of being a carer on physical and emotional wellbeing is well recognised. We need to take steps to look after ourselves every day. The pressures can also be cumulative so we may manage for many years but over time it becomes overwhelming. The metaphor of the [boiling frog](#) is a useful way of capturing this.

In this discussion we will consider some of the common emotional responses, both negative and positive before exploring the research into what can support our wellbeing. We will then discuss some practical tips that help and ways of connecting with others.

Common emotional responses

Parents commonly report mixed emotions that may vary day by day even minute by minute.

It can be helpful to name these.

Commonly reported negative emotions:

- anxiety, stress or worry
- depression or low mood
- anger & frustration
- helplessness & uncertainty
- sense of loss
- chronic sorrow
- guilt
- trauma

There can be many reasons for this: fighting for services, isolation, stigma and discrimination, as well as additional services in our lives (which can help but may also add to the pressures on us).

Guilt often layers on the pressure and it's important to treat ourselves with self-compassion and remember:

- No one is perfect
- We are only human
- Good enough is good enough

But life as a parent carer is not all negative either. Commonly reported positive emotions include:

- Grown as a person
- Put life into perspective
- Gained greater expertise, knowledge & awareness
- Made new friends who truly understand them
- Stronger and more determined to fight
- Enjoyment of, and pride in and love for their child
- Some report being 'a better person' with greater understanding, tolerance and empathy more broadly

Wellbeing as balance

It can be helpful to think of wellbeing as a balancing act. We have to keep replenishing ourselves in order to counter the challenges that come along.

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Through interviewing parent carers I identified the following common themes that supported their wellbeing:

- Finding a Sense of Purpose and Meaning – that will be personal to you, for some it was fighting for services for their child for others it was something unrelated to their child
- Positive Others – connecting with those that support us providing understanding and belonging
- Empowerment – knowing our rights, becoming more assertive and understanding our child's needs and how to meet them
- Child – our relationship with them, connecting and love
- Time that is mine – protecting time, everyday, for ourselves and to engage in activities that are supportive
- Replenish and Re-calibrate having a 'Swiss army knife' of self-care strategies – little and often
- Awareness – of our emotions, so recognising when we may be sinking, or need to catch up on sleep, or need to speak to someone else as well as awareness of the wider world and disability. – we can't control everything, life can be 'brutal' and complex. A wisdom.

Helping others

Many parent carers report the desire to help others, particularly other parent carers. This is an amazing trait in human nature and can empower us thereby benefiting our wellbeing too. Although care needs to be taken not to overload ourselves (i.e. with other peoples' problems) as if you have a tendency to take on too much it can become overwhelming.

Rescare have a new befriending scheme which you can find out more about by contacting their helpline.

Replenishing activities

Activities that you find replenishing will be personal to you. Here are some ideas that work for other parent carers:

- Coffee with a friend
- Yoga class
- Joining a club or campaign group
- Special day out with child or siblings
- Playing, writing or dancing to music
- Colouring in books or app on phone
- Writing or journaling
- Walk in nature
- Painting
- Mindfulness app

What works for you? How can you make time to do them today or this week?

Connect

You can follow me on social media and get further information on www.affinityhub.uk

My book Day by Day: Emotional Wellbeing in Parents of Disabled Children is available on amazon: www.amzn.to/3k1NReK

I also have a limited number of Parent Carer Wellbeing Gift Boxes available to purchase here: www.affinityhub.uk which include my book and a collection of pampering treats.

