

Self-Care

A Guide for Carers



About this resource

This resource has been written by a team of practitioners who have experience of providing care. Some of us also have experience of receiving care. In addition to care-giving and care-receiving, we have a variety of lived experience, including sensory impairment, chronic illness, physical disability, autism, ADHD, dyslexia and dyspraxia.

As well as incorporating our own experience of care-giving and -receiving, the resource draws on testimony provided by five care-givers providing care to loved ones in a variety of circumstances. Excerpts from their testimony - some quite brief, others longer - complement different sections in the resource and are also interspersed throughout the resource as a whole. The following paragraphs introduce these five care-givers in their own words and provide information about their care-relationships. We are very grateful indeed for their generous, candid contributions. The experiences of Angela, Linda, Caroline, Siobhan and Suzy add emotional depth as well as indispensable insights into what it is like to be a care-giver in a long-term care relationship. Other contributors to this resource have chosen not to be identified but were happy to have their testimony included.

Angela:

Angela is Mum and Carer to Cherry, her 36 year-old second daughter.

Cherry's older sister, Holly, collaborated with Angela on a dance they created to reveal Cherry through her own unique movements. Cherry is non-verbal but can express herself in many other ways, including her art, which she developed as part of Project Artworks who are based in Hastings. The creative drive in the family underpins the importance they give to connection and communication. Cherry taught them this and currently uses a Tobii EyeGaze tablet to make comments on the world as it passes by. The diagnosis of Rett Syndrome opened a world previously unknown to Angela but she has always believed that Cherry is more than her diagnosis. Together, they have participated in developing awareness and understanding between families and professionals. Cherry needs twenty-four/seven care, but is a strong personality and is loved by her family and team of carers who now help to support Cherry in the family home. Angela, her husband Barry, his mother, Audrey and a team of up to seven carers live and work together in a semi-detached council house in Eastbourne. It gets very busy!!

Linda:

Nia is 19 years old and lives at home with me, her Dad and her two older brothers on the family farm. Nia was born with Down's Syndrome and congenital heart defects. She spent most of her first two years in hospital and underwent major open-heart surgery at the age of 19 months. She has undergone further cardiac and corrective surgeries and has also been diagnosed with ADHD, autism and a profound learning disability. As such she requires total 24-hour supervision and support and is reliant on us to meet all her basic needs. I have been a registered learning disability nurse for 35 years and it was a real shock when Nia was born. I thought I would have all the skills to support her, but when the person you are now caring for is your own daughter, everything I thought I knew went out the window and I had to become Nia's Mum and not her nurse. The experience of caring for Nia has given me the opportunity to enhance my professional skills and the experience of staying with her in hospital ignited my passion to become the first learning disability liaison nurse in our local hospital. Over recent months my caring relationship has changed with Nia. I have been diagnosed with breast cancer and have undergone 2 surgeries and am currently receiving chemotherapy. I am therefore unable to provide so much of the hand-on care which has now been taken over by my husband and sons (but am still able to enjoy her lovely hugs and sloppy kisses).

Caroline:

My husband's 94 year-old mother, Mary, lives with us and he and I share the care-giving role (he is the main carer, though, as I work in the week). Mary probably has dementia but is unwilling to be assessed as she has a lifelong dislike/fear of doctors and will resist visiting them unless absolutely essential. Most of the time, she doesn't know what time of day it is, whether she has just got up or if it is evening. She has severe short-term memory difficulties, basically she can't remember most things once they have happened. For example, she will forget she has been out for lunch almost as soon as she gets home, and she can't remember family visits, so thinks the family are not contacting her. Mary hates being seen as 'old', despite her age, and can't remember how old she is - she is shocked when she asks and we tell her! She often doesn't recognise herself in the mirror. She used to be very fit and active and was a very good ballroom dancer, which she did well into her 80s with her husband. She used to enjoy cooking, was a very good dressmaker, did her garden into her 90s, knitted all her children's clothes, loved car boot sales and getting a bargain in the charity shops. She worked most of her life, after her children were older, on assembly lines in factories, mostly. She never had much money and now can't understand or retain that she has enough to buy herself nice things and is often worried about not being able to afford her bills - this can be a big stress for her so we don't discuss it if possible. She has always looked after her family and helped everyone out, and this is important to her, along with being independent, although most of the time she seems not to remember or think much about her family unless they are actually there with her. Mary needs support with things like continence, in terms of prompts and reminders, and with changing clothes, eating, drinking and going to bed. If we didn't provide food and drink, she probably wouldn't eat or drink, which is why she ended up in hospital after she had several falls at home. I think this is largely linked to her memory difficulties, as she lives 'in the moment' at all times. Conversely, she can remember things she worries about. For example, Easter was a big trigger and she was very stressed as she couldn't remember that she'd already bought Easter eggs. Mary has no insight into her difficulties at all, is in total denial that she has memory loss, thinks she can walk up stairs, do the housework etc! Therefore she has no idea why she can't go home, which is another challenge and a trigger for difficult times. She also has heart failure, breast cancer, a fractured hip and is very deaf, but she can't retain this information and gets very cross if we tell her, so we've given up! The biggest challenge is that we don't have separate living spaces so Mary is always in the lounge and there is nowhere for us to have space or for her to settle, so when things get very busy (which they often do), she will get very stressed by all the activity and this triggers difficult times (repetition, saying she needs to get home, agitation etc).



Siobhan:

I am Rupert's mum and full time carer. Rupert is a surviving twin born at just over 23 weeks gestation in 2015. He spent nearly 5 months in NICU (neonatal intensive care unit). He has severe cerebral palsy, epilepsy, cortical visual impairment (no functional vision) and has a PEG feed (a feeding tube that goes through the abdomen into the stomach). He is non-verbal, non-mobile and has PMLD (profound and multiple learning disabilities). Rupert also has gorgeous blue eyes, an infectious giggle and the sweetest most loving nature, with quite a bit of sass too. He loves listening to Mr Tumble and Shakira. He needs 24/7 care and monitoring for all his needs. Paul is Rupert's dad and Felix is his half-brother.

Suzy:

I'm Suzy, mum to Kip who is 9 years old and Miller who is 16 years old. Kip has diagnoses of Phelan-McDermid Syndrome and autism, he presents with a significant learning disability, significant communication disorder and significant anxieties. He needs 1:1 support during all his waking hours. With the right support, Kip is enthusiastic, engaging, participatory, adventurous, cheeky, opinionated and a complete joy to be with. His brother's equally fabulous too!

Underpinning the information provided in this resource is the principle of co-regulation - the reciprocal process whereby care-givers and care-receivers support each other's regulation and wellbeing. We believe that care-giver wellbeing is one of the most significant, yet frequently overlooked, factors in the wellbeing of the care-receiver.

Sitting down and having a chat with someone who has walked a similar path in caring for a family member, friend or loved one can really help us when we are feeling overwhelmed. It is our hope that this resource offers some of that sense of comfort we experience when receiving support from a peer - even if we are not able to sit alongside each of you and share a cup of tea and a chat.



Disclaimer:

The resources and strategies put forward in this text are offered as suggestions only and should not be construed in any way as advice, recommendations or proposals for action. If you are experiencing difficulties in your caring role, you should consult your GP in the first instance.

The caring path

Suzy:

Caring for Kip has given me a lot of happiness. I get a lot of joy from sharing experiences with Kip - endeavouring to give him an interesting and engaged life, and to give him confidence in himself, is really motivating for me. He gives a lot back in terms of affection, enthusiasm and engagement and he is always progressing. He makes me slow down and take notice of all the small things in life that are often the important ones, and I'm talking literally, for example, how hard it is to say 'walk', the steps of making porridge, the best way to cut a bramble... Caring for Kip means that, in my life, I have less sleep and more worries than perhaps I would otherwise. I have learnt to be more empathetic, to think deeper about people, rather than judging them. Kip is like a barometer for finding the good people and also the best in people - I love to see that happen.

The experience of caring for another person differs from one care-giver to the next - sometimes markedly so. For example, the challenges presented by caring for a child with a learning disability are different to those associated with caring for a parent with dementia. The former experience may entail a sense of grief for the future that the parent had envisaged for their child, whilst the latter may entail a sense of loss for the parent they used to know.

Suzy:

I had planned to retrain shortly after having a second child - I have looked into many courses and the outcome is always that I'm not able to take that much time out to be at college or to be able to afford the training. As a result, I find myself repeatedly having a mix of part-time, flexible jobs. I like to work as it makes me feel good to earn my own money, be creative, socialise with others and use my brain in a variety of ways. I would prefer to have one job that I can focus more fully on but I've been unable to work out what that is - my brain buzzes with different ideas. I tend to give 110% to everything and of course when that is a variety of things it can get overwhelming.

For some people, caring may come easier and more naturally than for others. Some of us may struggle and feel unable to cope. Some people choose to care for another person, whereas others may find themselves on a path they never imagined they would have to take, taking on a caring role as a result of circumstances. For some, their caring path unfolds slowly and has been foreseen. For others, their caring path starts abruptly and the conditions of their life change suddenly, a life change that may be experienced as a shock to the system. For some carers, the role may be enriching, for others it may feel stifling and suffocating. Some carers may feel valued and appreciated in their caring role, whilst others may feel taken for granted. Some may feel content, others angry, guilty or isolated. Some may feel anxious, some depressed. How we feel may change gradually over time, or sometimes frequently over the course of a day.

Siobhan:

I think it is a cliché, but I think caring for Rupert has given me perspective. Obviously, when you are dealing with someone with such acute and complex needs, then it draws focus into the everyday and each hour of every day, and the wider context that other people may be judging their lives by - the milestones, the inch-stones - they have to go to one side, and you have to live a completely different perspective and a different context. And I think in that sense, there's a freedom, actually, that comes with this caring role. Whilst in many ways it's very difficult, and in many ways it's the opposite of freedom - it's limiting, it's difficult, it's restrictive in many ways - there's also a liberation in that, in that you are very much walking your own path, because Rupert, you know, he doesn't ever meet... there are no milestones, even within the severity of disability that he has.

So you know, professionals will come in and ask questions – does he do this? does he do that? - and I think that can be incredibly difficult, when you have to say 'no' to everything – 'No, he doesn't. No, he doesn't. 'No, he can't. No, he can't' - but in that, I think it's given me the ability to just be his mum. I think a lot of it is around learning to be resilient and to self-care, but to the point of self-preservation, and it draws focus on to – again, as clichéd as this sounds – all the most important people and things in life, because you just don't have the capacity to think wider, and often thinking of the future is really scary, so it is easier just to think of the day and to be where you are.

Whatever the circumstances that have given rise to your becoming a carer, one experience that most carers share is the feeling that they simply need to keep going, to keep on supporting the person they care for. Rest, respite or stepping away from your caring role for a spell may feel like it is not an option - indeed, for many carers, it simply is not an option. To be needed to such a degree - to be so integral to the wellbeing of another person - can feel wholly overwhelming, physically as well as psychologically. It can leave us feeling as if there is little or no scope for time for ourselves. We may feel as though we are treading water, with no option but to keep on going, day in, day out.

Siobhan:

Everything is quite a conflicting emotion. I think that's because everything does feel... within the moment, there are two quite different, or three or five or ten different emotions. In many ways, in all honesty, it's taken an immense, immense toll. It takes a huge toll financially, which is a stress, but obviously in a much bigger sense it takes an emotional toll, psychological toll, mental toll, physical toll. I think you're living with a constant sense of grief, or impending grief, grief for what has been lost and also for what may be ahead, living with the uncertainty of what's ahead. You live in a world where the word hospice is mentioned, you live in a world where children at Rupert's school have passed away. We live with that, and that's heavy, and that's difficult. The toll is also... in a physical sense, I did my back in recently from lifting, and I was unable to stand or walk, really, for six weeks, in agonising pain – and that could happen again. So you have to learn new ways of being and working and using hoists and different ways of handling. Just getting up, the lack of sleep, I've cur-



Stress, adrenaline, it always feels like there's something new, a new diagnosis or a new treatment. Rupert had an annual review recently and he's currently awaiting six referrals for different things and all of those things need to be navigated and understood and they're all different parts of medicine. So you know, there's physio, there's OT, there's epilepsy, there's nutrition, there's multiple teams, and all of it needs to be navigated. So, and then obviously, there's day-to-day life, and we're very, very restricted because Rupert doesn't like to be in his chair, he doesn't like to go in the van, so you're very restricted as well – much of my life and his life is in the house.

Added to that, obviously, I've got ME, so that's an additional thing, but in a caring role, it's difficult, you know. I have friends at Rupert's school that do go out and do other things, so it's not per se to do with Rupert's disability, but it has to do with the presentation of his disability particularly, and what he likes to do, and he doesn't want to be traipsed around in the van and strapped in a chair and taken to things that, in all honesty, don't mean anything to him. He prefers to be at home where it's quiet and it's calm, but that's then restrictive on the whole family. It means that we can't often do things as a four. I think in every sense there's a huge toll, but equally, there's immense love and there's immense ability to live in the moment and there's immense moments of complete joy. And Rupert's such a character. You know, he's very much an individual, and I think that those things live and stand side by side – it's immensely difficult and it's immensely loving and immensely joyful. And I think, for me as a carer and a parent, it's learning to sit with that conflicting emotion and know that you will feel both those things at any one time and that's okay. And it's okay to say those things. I think there's a taboo around this area of care and children, and we're not meant to say it's hard, and we're not meant to say it breaks your heart, and we're not meant to say all these things, but it does. But it also fills your heart at exactly the same time, and I can look at things and think, isn't that incredible? He's just now learning how to respond to 'hello' in a consistent way, it's absolutely amazing. But would I like him to be saying 'Mummy' and running around me and going off and doing this and that and the other? In exactly the same moment that I'm proud that Rupert, at the age of seven, can make a noise consistently to the word 'hello', I'm also grieving for the fact that I'll never hear the word mummy and I'll never have a conversation with him. And those two things can sit next to each other and you can feel them both and they're both hard, but they're okay. And that's okay. So I think when we talk about the toll of caring, it's multi-layered, multi-complex, and it varies hugely – because of how much sleep you've had, how much support you're getting, how much the services are working for you, how well he is at a given time, how many referrals you have at a given time – and so it will change, as in everyone's life. But I think that our life with Rupert is more acute and I think that's the difference.

The idea behind this resource is to offer a different lens through which to consider your caring role. In writing this resource, we started out from the premise that your wellbeing and the wellbeing of the person you care for - whether that person is a family member, friend or loved one - are intimately connected via the process of co-regulation. In a nutshell, co-regulation can be characterised as the little things that two people in a caring relationship - of whatever kind - do for each other to support the other person to feel safe, valued and regulated. For example, when we bring a cup of tea and a biscuit to our partner or loved one, their smile of gratitude lets us know that our action has regulated them, and, in seeing their smile, we ourselves are regulated.

More formally, co-regulation refers to the process of reciprocal attention and support that occurs between two or more individuals. The term was originally a description of adult support for infants, but is now used to describe an interactive process of regulatory support that can occur within the context of caring relationships across the lifespan.

Suzy:

The degree of correlation between my state of wellbeing and Kip's is probably 100%. It's more to do with my state of wellbeing affecting both of us – how I feel and how I care affects both of us. Kip's state of wellbeing can and does obviously fluctuate, but if I'm okay then I find I can keep an even keel however Kip is presenting. In the last few years, I've made a much more determined effort to look after my own health. I've realised that looking after my own health improves my mood, my sleep, my self-confidence, my fitness and health. Getting to sleep, and staying asleep, was so awful that I kick-started the process by having a couple of sessions with a nutritionist who gave excellent, sensible advice. Lots of stuff I knew but it helped having someone tell me and keep tabs on how I was doing. Cutting out caffeine completely and reducing my sugar intake have probably brought the biggest change – hugely reducing the feelings of stress and urgency that I used to get.

Linda:

Without a doubt, there is a correlation between our wellbeing and Nia's. I have recently been unwell and had surgery which resulted in me not being able to do any "hands on care" with her which really affected her mood and behaviour. Also, if she is having a particularly difficult day, it can often affect how I feel, sad that I can't help her or cross if she has caused physical damage/broken things etc. I can usually tolerate so much, but if things are really bad it gets too much.

Caroline:

The degree of correlation between Mary's wellbeing and ours is probably quite high. If we are busy, stressed and rushing around, which is often the case with a busy family, she thinks something is wrong and gets agitated. This then makes us stressed and things go round. She is happiest when we are doing nothing and sat watching her TV with her.

Taking this key principle of co-regulation as its starting point, this resource will help you to identify - and to prioritise as part of your daily routine - small, sustainable actions and activities that promote your self-care and improve your health and wellbeing. By practising regular and meaningful self-care, we make of ourselves a more effective co-regulation resource for the family member, friend or loved one we care for. As we become more reliably regulated, so too does the person we care for, and, to the extent that we maintain our self-care practice, this reciprocal process continues in a virtuous circle.

For many carers, prioritising ourselves in this way does not come easy, it somehow goes against our instincts. At the same time, we know intuitively that, when we are in a caring relationship with another person, it is essential for the carer to feel okay in order for both parties to feel okay. Think of when you are on an aeroplane, about to take off to go on holiday, and in the safety briefing the cabin crew instructs you to put your own oxygen mask on before helping anyone else to put theirs on. In order to be able to attend to the safety of a person who is more vulnerable than you, you first need to ensure that you, yourself, are safe. However, despite knowing this, as carers, many of us either feel unable to take time for ourselves or feel riddled with guilt if we do. This resource provides tools and strategies you can use to recognise how you are feeling (what is my state of regulation? why do I feel this way?) and to take simple, doable self-care steps that improve your wellbeing and resilience.

Angela:

Stress is our response to disruption. Sometimes it is sudden - an emergency - which I have always found easier to deal with. A medical emergency puts all expectations of a 'normal' day/night out of my mind and I enter the continuous present of the emergency. I experience Fight (for my daughter) and Flight (giving me the stamina to keep going to get past the emergency) and when all is resolved I have experienced something that has passed.

Much harder for me to deal with are the drip, drip of micro-stresses that, over time, take their toll. Stress, as a state, can be damaging and lead to serious physical and mental health consequences. The repetitive physical tasks of caring can wear the body down and cause damage, but the state of stress - ongoing, unresolved stress - is what the body and mind does to itself and this is what can lower our capacity to manage the impacts that our caring role delivers to us. Everytime I feel myself losing my equilibrium, I take it as a cue that it's time to see myself as a priority.

Suzy:

The other hardest bit is when I am really tired or not in a good mood because of an external reason not to do with Kip. I have learned I need to be more self-aware and acknowledge that "I feel like this today because..." and that these are the times that I can find Kip the most demanding and noisy to be with. It sounds simple, but I firstly tell Kip how I'm feeling and "sorry I'm in a rubbish mood" type of thing. Whether he understands or not it does seem to help me saying it aloud rather than holding it in.

And secondly just try and keep it together and think of activities we can do where my needs to 'mentally take time out' are met, but Kip can also be present, for example going outside helps to refresh and calm both of us, so we might go to the woods, take a flask of tea and take ages slowly collecting pine cones to take home or sticks to make a pile; go on a return train ride; do some baking together or put on Mr Tumble or a documentary about bin lorries for Kip and cuddle next to him. On usual days, I talk to Kip about all sorts a lot and am enthusiastic, but when I'm feeling rubbish, I just try to be quieter, keep myself calmer and respond slower.

Stress and its effects on our physical health and psychological wellbeing

Caroline:

Caring for Mary can be very stressful, which increases general tension in the home. People can't relax if she is in a state of mind where she keeps asking to go home. We don't really have anywhere for Mary to sit apart from the family lounge so this means nobody gets a break. We can't really go out as a family for more than two or three hours as we can't leave her with food or drink as she will try and carry the plates into the kitchen and this makes her fall. Then there is the worry that she might have fallen over when we go out. We can't really plan any holidays at the moment as we have no carers and no respite.

Those of us who are not carers nonetheless have a sense of the considerable stress that carers experience in their lives as a result of their caring role. We can readily imagine the sense of responsibility that is part and parcel of the caring role and that exerts its own stresses. However, many of us may not fully recognise the extent to which each and every of us is exposed to stressors over the course of our days, nor the impact that these stressors can exert on our wellbeing and our physical and mental health. In this section, we look at micro and macro stressors and the impact these can have on our physical and mental wellbeing in both the short and long term.

The long-term effects of exposure to stress can be harmful to our physical and mental health and wellbeing. Providing unpaid care to others is increasingly recognised as a social factor in determining health (Public Health England, 2021). In terms of physical health, experiencing significant stress contributes to the development of obesity, type 2 diabetes, high blood pressure, cardiovascular disease, stroke and Alzheimer's disease. Stress can be a factor in insomnia, burn-out and auto-immune disease. In addition, stress plays a role in many mental health conditions such as anxiety and depression (Chatterjee, 2018).



Siobhan:

The physical side of caring for Rupert is becoming increasingly difficult. My back went, I'm physically exhausted, Rupert doesn't stop moving. We've got a new carer who's just started this week so I'm training him a bit and he was watching me hold Rupert and he just said, 'my God, it's like you're at the gym!', and it is like being at the gym. I mean, Rupert's strong, he doesn't stop moving, he constantly needs repositioning, he doesn't want to sit in a chair, he needs Intensive Interaction and intensive attention all the time. And whilst it's lovely that he's interactive, it is also very, very physically exhausting. So a lot of lifting, a lot of moving, a lot of straps tied up and stuff. I'm currently having to teach myself to transition, with Paul and everyone, to use the hoists at home, he's having a sleep system at home. So there's lots of things, but all of those things are difficult, emotionally, because you don't want to start to have to lift with hoists, it loses the love of just picking him up. Holding him is becoming difficult and so it's becoming more clinical, and therefore it feels like you're becoming more formal with your own child.

Years ago I read an article by a mum and she said the two things she wished she'd done sooner, and more consistently, were help with her back - massage, chiropractic work - and counselling. And she said she wishes she'd accessed both of those things, like, day one. And I sort of took that in and didn't really do anything about it, and now I feel, you know, both of those things would be incredibly useful. If I was able to have my back looked at twice a month and access to counselling as well, but really specialised counselling where you don't have to explain and you don't have to feel the guilt of the emotions that you're going to talk about, and I think that's quite hard, and I'm yet to find that person, and again, it's money, you know, we don't have the money for that, for either of those things. So physically, I think that's one of the hardest things. Strategies for that are massage, chiropractic work, being taught proper manual handling, but gently, taking into account the emotional narrative that comes around that as well.



And the other hardest things are obviously the emotional side of caring for Rupert, which are just like a box of emotions. It's being able to recognise that it's very... every emotion is quite conflicting, and every moment is joy and sorrow mixed, or grief and future together, or loss and hope together, and it's okay to say it's hard and it's okay to be honest about all of that because it doesn't mean you don't love your child, it doesn't mean you wish your child was different because you do, of course you do, and anyone that says they don't, I can't understand, because you wouldn't want that for your child.

That's not to say we don't love him with every sinew of our being, but that's not how life is meant to be, as such. So I think it's okay to say that, I think it's okay to be honest, I think you have to be honest, and I find it sort of bizarre, really, that friends are able to moan about their kids to me, or on Facebook, 'oh my son this, my child that', but there's a taboo about that with special needs children. You're not really meant to do that, you're not meant to say, 'oh, so and so was a right old pain today.' Well, why not? You know, there are lots of things with Rupert that are not to do with his disability, they're to do with the fact he's quite impatient. And that's it, that's who he is, so we can't go around trying to iron out his personality because he's disabled. He might be really annoying at times, and really impatient and have strops and be moody and have a temper, and, you know, that's him, there'll be aspects of me and aspects of Paul. And so I think it's allowing Rupert to be himself, not always medicalizing him, allowing us to feel all the emotions that we have, because the hardest part is having to pretend, and the hardest part - and I have a whole thing about this - is the 'heroisation' of special needs parents which is really damaging and toxic because it doesn't allow you to be yourself, and it doesn't allow you to be, not even... the word isn't weak and strong... just yourself. And there's this hero worship, people say, 'oh, I don't know how you do it, I couldn't do it'. Well, you could, because it's your child, and it's not a choice. When people say, 'you're incredible', well why? And I'm not being flippant, I don't like toxic positivity, it's awful. And I think it's the same in special needs, there's a heroisation of the children and there's a heroisation of the parent-carer, and there's a real danger in that because that doesn't allow for us to fall to the floor and cry and say, I can't do this any more.

It doesn't mean you don't want to do it, it doesn't mean you can't do it tomorrow, it just means that, at that point, you don't feel you can do it any more. I think the hardest thing is having to mask, essentially, and to pretend things are okay and to say 'oh, you know, it's okay because...'. Well it is, and there's huge amounts of joy and love and everything, everything that every family has, but every family has those days that are really crappy and they don't like their kids that day. And I think, we're not allowed to have that and I think we should be, because then it allows everyone to just feel a little bit more 'normal' and less alone. And I feel really quite strongly about that and I think that is one of the hardest things, the hardest thing is being almost worshipped for just loving your child and doing the best that you can do, and we're all trying to do that. Everyone, not just children with a disability, but every parent. But I think we get almost put into a different category, and therefore, by being put into that category of special needs parent, you're put into a category of, firstly, 'the emotions you're allowed to have', and secondly, 'the emotions you're allowed to express', and that is where the damage is, that's the hardest part, that's what stops people accessing help and that's what stops people asking for support from official services but also from friends and family. So for me, that's probably the hardest thing - firstly, learning to live with and sit with a huge, huge array of conflicting emotions, and then, secondly, to be able to be honest about those and open about them.

Laura:

For me the hardest bit is all about how other people make me feel. I feel leaned on by certain members of my wider family and a few particular friends that I am not doing enough and that I should be working full-time (like them), be more ambitious for myself and more productive (like them) and be more selfish with my choices (like them). For some reason, as a carer you are open to others thinking they can advise you. They may feel well-intentioned but their opinions come from a place of not being a carer themselves and so not understanding the position I am in and the choices I have made. I feel they look down on the caring aspect of my life. And still the subtle (and not-so-subtle) drip-drip-drip of their comments regularly undermines me and makes me feel like I am not good enough and that I should be doing more and that I should be pursuing a big full-time career again like I used to have before my daughter was born. It is something I find hard to keep out of my mind and often makes me feel down. To be honest I haven't learned any truly effective strategies to deal with this. I have more friends who say I am doing enough and have also received good advice to not heed their opinions but, in the moment, I have never been strong enough to counter them verbally. Perhaps it's because I, too, feel I am not doing enough either. I've learned that some people make you feel good about yourself, some don't. It's best to lose the latter but it's not always that simple if they're family.

Many people do not even recognise or acknowledge the stress they are under and, as a society, we have begun to accept stress as simply a part of life. Being busy is increasingly equated with being seen as 'successful' (Chatterjee, 2018). The World Health Organisation refers to stress as 'the health epidemic of the twenty-first century' (HCA Healthcare, 2023). Chatterjee (2018) reports that up to 80% of GP appointments are thought to be related in some way to stress. In order to be in a position to address the micro and macro stressors in our lives, we need to be able to recognise them.

Stress is sometimes positive in the sense that it can keep us safe. Throughout history, humans have been exposed to stressful situations and we have developed survival strategies to keep ourselves safe from harm. For example, if we think of our stone age cousins, they were confronted by life-threatening situations, such as being preyed on by sabre-toothed tigers. When we perceive a threat in our environment, the release of stress hormones and immune system messages prepares us for fight or flight. This involves slowing down or suspending non-essential systems such as digestion and sex drive, whilst ramping up systems that support quick decisions and high-energy responses: our heartbeat quickens, our blood pressure rises and our senses sharpen and tune into any perception of threat in the environment. In situations when we face a significant threat to life, these automatic survival strategies are life saving.

Our stone age cousins experienced significant threats to life only intermittently, and these threats were readily identifiable (a rampaging mammoth, a hungry sabre-toothed tiger). By contrast, since the industrial revolution, human life has changed at an accelerated pace to such an extent that our lives would be unrecognisable to our stone age cousins. Our lives are now punctuated by frequent and multiple stress factors that we have not physically evolved to deal with. Many of us are spending more time in a dysregulated stress state rather than a regulated thrive state, and this is having a negative impact on our mental and physical health.



Healthy short-term stress responses and their dangerous long-term effects

Healthy short-term stress response	Long-term harmful effect
Raised blood pressure in the short term helps transport blood to the brain	Chronic high blood pressure increases the risk of many diseases, such as heart disease and stroke
Increased blood clotting helps save your life if you have a bleeding wound as the bleeding will stop more quickly	Long-term tendency for the blood to clot increases the risk of having a stroke, heart attack or deep vein thrombosis
Increased insulin resistance in the short term means that your body won't store any sugar in your liver and muscle cells. It results in more sugar staying in your bloodstream, which means that more is available for the brain	Long-term insulin resistance contributes to the development of type 2 diabetes, obesity, high blood pressure and the production of harmful types of cholesterol
The body's resources are directed at making the stress hormone cortisol to help deal with the immediate threat, at the expense of the production of sex steroid hormones such as oestrogen and testosterone	Long-term diversion of resources to make cortisol will lead to hormonal imbalances and contribute to a wide variety of hormonal issues such as a lack of libido
The body's resources are directed away from digestion as this is a non-essential function for survival in the moment	If bodily resources are diverted away from digestion for too long, digestive complaints such as constipation, bloating, indigestion and Irritable Bowel Syndrome may ensue
Small amounts of cortisol improve our brain function, which allows it to function better in a short-term stressful situation such as if attacked by an animal or when we want to perform well in an exam	Prolonged release of cortisol starts to kill nerve cells in the hippocampus (the brain's memory centre) and may increase the chances of developing Alzheimer's
The emotional brain being on high alert to look out for threats is a good thing if you are in danger	If this becomes long term, it will make you more prone to anxiety, as you start to worry about everything and see threat when no threat is present

(adapted from Chatterjee, 2018a: 18 -19)

Angela:

To be a carer is to be familiar, possibly intimately, with depression. Depression may land from the shock of a tragically unexpected shift in circumstances that leaves you and your family derailed, or it may settle silently around your shoulders as you try to fulfil a daily round of tasks that never seems to move any closer to resolution.

I experienced prolonged bouts of depression. I became so finely tuned with my daughter that sometimes I wondered if it was she who was depressed and I who was picking up feelings from her. Eventually I realised that I would need help to lift myself out of the depression enough to be able to care for her in the way I wanted to. This was my 'putting my own oxygen mask on first' moment.

Later, I learned to welcome the messages of depression as they were a strong indication that I was becoming unrealistic about my capacity to keep going and it was time to take care of myself and take a break, or risk serious burnout. My awareness of myself in the caring role grew from all the hard experiences I faced, gradually learning that I could not - should not - be doing it alone. This is one of the real dangers in caring, where trying to manage alone will add to the difficulties. Finding allies feels impossible at first, but they can appear from almost anywhere.

Depression is often characterised by low mood, indifference to our situation and anhedonia (an inability to experience pleasure). However, some medical professionals now believe that depression may be experienced as a product of inflammation in the body caused by survival responses to the stresses associated with modern life (Kings College, London 2016). This study is beginning to change perceptions in the field of progressive medicine.

Stress states and thrive states

The human brain is always processing information - information from the environment around you, as well as signals from within your body. This is a dynamic process that changes constantly in response to what is going on in the environment at the time. Signals from within your body tell your brain about the state you are in, for example changes in your breathing can signal whether you are relaxed or anxious, your hormone levels can tell you if you are ready to run or if it is time to go to sleep. Signals from within your body in response to information from the environment help you to understand whether we are facing a threat or whether we are, in fact, safe.

As human beings, we spend our waking hours in a thrive state, a stress state or somewhere in between. In a thrive state, we are able to rest, digest, attend to tasks, learn, de-stress and sleep soundly. In a stress state, we are responding to a perceived threat - we are focussed solely on dealing with the threat and keeping ourselves safe. It is our autonomic nervous system that sets our state of regulation, whether that be a thrive state (when we feel safe and we are calm and alert) or a stress state (when our survival responses of fight, flight or freeze are activated). Our autonomic nervous system has two branches - the sympathetic nervous system (SNS) and the parasympathetic nervous system (PNS) - and controls those bodily processes that we don't consciously manage, such as our breathing, heart rate, perspiration and so on. When we are in a situation of perceived threat, our sympathetic nervous system is activated and we enter the stress state. Simultaneously, the stress hormones cortisol, adrenaline and noradrenaline are released that prepare the body to deal with the perceived threat either by fighting or fleeing. Once the threat has retreated or has been dealt with, we return to the thrive state governed by the parasympathetic nervous system.



The way we process information from our environment changes when we move into a different state. Broadly speaking, we can think of the human brain as having evolved sequentially and hierarchically (the oldest part at the bottom and the more recent, more complex part at the top). The older part of our brain is often thought of as our 'emotional brain', the part that processes our feelings and emotions. The evolutionarily newer part of the brain is considered the 'rational brain', the part involved in logic and reasoning. When we are in a thrive state, the rational brain is in control and we can make decisions, learn, problem solve and so on. When we are in a stress state, however, our emotional brain takes over, responding rapidly to the demands of the situation. This is exactly what we would want to happen if we needed to protect ourselves from threat and to keep ourselves safe.

Our amygdala, an almond shaped structure deep in the brain, scans the environment for threats and danger. The more frequently the threat response is activated, the more the brain, through the process of neuroplasticity, is primed to respond to perceived threats. Given this, it follows that the more frequently the brain experiences threat, the more likely the brain is to perceive threat, and this can occur increasingly when there is no actual threat in the environment. This is when a 'state becomes a trait' (Perry and Szalavitz, 2017): our brain becomes so used to being in a stress state that this becomes our default state, with the result that our emotional brain influences our responses more readily than our rational brain. This is called having an SNS (sympathetic nervous system) bias.

We can use the plasticity of the brain - its capacity to become modified in response to experience - in order to offset the negative impacts of stress on our mental and physical health. By seeking out experiences that reliably activate our parasympathetic nervous system (the one that puts us in the thrive state), we can, over time, 'reset' our brain to respond only to actual threats in the environment rather than to those perceived threats we respond to when we spend too much of our time in a stress state. By working with the plasticity of the brain in this way, we can, over time, support a PNS (parasympathetic nervous system) bias. This resource offers information and ideas about how you can reorient your nervous system bias, away from an SNS bias (stress state) in favour of a PNS bias (thrive state).

Suzy:

I aim to keep one day a week – Friday, during school hours – for myself to do things I wouldn't otherwise have time for. I do an exercise class first thing then maybe meet with or phone a friend for a long catch-up, go shopping with my mum, make myself a nice lunch and sit quietly in the garden or go for a good stomp with our dog in the countryside.

Siobhan:

I think when we're most comfortable, it's probably just the simplest of times, the simplest environment – at home, by the fire, on the mat, Rupert's got Mr. tumble and he's responding, I'm sitting near him, with him, we might be doing stretches, we might be doing Intensive Interaction – which is lovely because he's really developing with that – connecting with him. I think also, it's very rare, but it's times we're able to go and do something as a family, the four of us, and we have someone with us, to help. And I think that then allows me to step down a bit, and to be less vigilant all the time. Probably one of the best times we've had recently was last summer, a friend of my sister's lent us her house in Dartmouth. Our night-carer for three and a half years - she became part of the family – came with us for the whole six days and she did each night for me, which just made... I can't even explain the difference that that made. And then in the day, after she'd had a sleep, she'd also hang out with us, and it just meant that we were able to be a four, a family, with her helping. And I think those are the times, I guess you feel more like a family and you just feel like you're all together. And Rupert loves it, I love it, Felix absolutely loves it and Paul loves it.

The experience of stress as part and parcel of modern living

As humans, our bodies and nervous systems have not evolved to manage the stresses associated with modern living. Although we are unlikely to experience life-threat in the way our stone age cousins did, our bodies nonetheless respond to stressors, both micro and macro, in the same way. Many of us nowadays are living in a stress state to which we have become habituated and it has been shown that carers live with more stress factors than the general population (George et al, 2020).

Stress factors associated with modern living include:

- Dealing with social isolation
- Dealing with bullying and stigma
- Deadlines at work or school
- Being constantly accessible to others via smartphone
- Financial worries
- Factors of urban living such as overcrowding, fewer green spaces, commuting
- Living in smaller family units with less access to extended family support
- Putting your body through stress in the gym
- Working on computers and in artificial light
- Checking emails and experiencing multiple demands on your time
- Dealing with workplace pressures and family
- Technology allowing work to colonise home life
- Limited time off work

Linda:

Nia is totally dependent on us to meet all her needs, changing soiled incontinence pads when she doesn't want to can be difficult. It usually takes two of us to change/bath her when faecally incontinent. The constant vigilance and always being there is also very demanding which is why respite is so important. When Nia is particularly distressed, I always try to see it from her side and try and work out why she's behaving as she is – is there a need I haven't met, is she ill, does she want to get out of something? But sometimes it just seems that she wants to be horrible and deliberately difficult eg stripping and smearing. Thankfully these episodes are few and far between and I try to think she will be in bed later and tomorrow will be a better day.

Micro stressors

Micro stressors are the small doses of stress that we experience over the course of our day. They can be triggered by things as simple as a pile of washing waiting for you to deal with it, the sudden sound of your alarm clock or the ping of another email coming in that needs to be read, to name but a few. We may not recognise these as stressors as such, but each has the potential to activate our stress response if we are already feeling overwhelmed by what needs to be done or by what is expected of us. These micro stressors are frequent, repeated and can feel relentless. Cumulatively as well as individually, they may activate our stress response.

Modern life, for all its labour-saving devices, increasingly creates additional pressures and expectations on us. The increasing pervasiveness of technology has eroded the experience of quiet and stillness in our lives. We are at all times contactable or reachable by those who want us, need us or wish to sell us something. This perennial contactability can cause stress and eat into our free time.

If this is what it is like for the general population, those of us who are carers experience more than our fair share of micro stress doses. As care-givers, we have to deal with the multiple demands of our own lives as well as those of the person we care for.

By the very fact of requiring care, the care-receiver may have educational, health and social care needs that mean their care-giver has to undertake significant amounts of administrative work with a variety of services and organisations. As such, caring for another person can entail substantial cognitive and emotional loads that often are neither seen nor acknowledged.



Tasks you may carry out for the person you care for might include:

- reading and writing letters or emails
- requesting services
- liaising with educational, health and social care professionals
- attending meetings
- accompanying the person to medical appointments
- advocating for the person's needs
- managing finances and organising benefits
- supporting social connections
- providing companionship
- ensuring essential and practical needs are met (shopping, cooking, cleaning)
- ensuring that the person is receiving services they are eligible for
- providing personal care
- providing sanctuary and support when someone feels unsafe
- co-ordinating access to further support such as respite
- providing care whilst holding down a job or running a business
- providing care whilst managing your other family responsibilities.

Siobhan:

There's so much admin that goes with caring for a child with this level of complexity. He has probably eleven medical teams, so I have to negotiate and navigate all of those, all the paperwork, all the admin, everything, every piece of equipment, everything, so it is a full-time administrative job as well. The whole system is labyrinthine, difficult, doesn't make sense, all the time. And everything is a battle, so every service you try to access is a battle – I've not had to battle too hard, but I know people that have, and I do have concerns that the reason I battle – and I do battle – I don't know how to put this, but the reason I think I am able to navigate it is because I come from a world of that kind of fluency, and I will put my arguments forward and they will be thought out and they will sound calm and they will sound sensible, and it's how you approach it. My social worker for Rupert said to me the other day, yes, it is often parents who shout louder. But actually, it's not that, it's the parents who put forward the most straightforward, calm arguments for things that end up being heard above people that, through no fault of their own, are not able to access services in the same way.

Chatterjee (2018a: 23) describes modern life throwing 'a barrage of micro stress doses' at us that disrupt our biological and neurological systems. This onslaught of micro stress doses can mean that you perceive threats in the environment where there are none. This heightened susceptibility to perceiving and responding to threat means that you become more vulnerable to new stressors as you are perceiving more threats than there are and responding more readily to such threats, a process that Chatterjee describes as a 'feed-forward cycle' (ibid.) and one that can lead, over time, to your becoming unwell.

Macro stressors

Macro stressors are significant stress or trauma events that have occurred in a person's life. For many carers, the start of their caring journey may be the result of a macro stress dose such as a loved one having an accident or experiencing life changing illness or the diagnosis of a child's long suspected disability. The nature of the caring role means that we don't always have time to process what has happened. In addition, many of us will have experienced trauma at some point in our lives and this may still be exerting an impact on our wellbeing.

If you have experienced a macro stress dose in your life, you may be more susceptible to the impact of stress across all areas of your life, and as a result may feel the impact of micro stress doses more acutely. Some macro stress doses such as adverse childhood experiences (ACEs) may have an impact on us that we are not even conscious of until something triggers a reaction in us.

We hope that this resource provides you with ideas to improve your wellbeing. We also hope that it may play a part in supporting you to spend more time in your thrive state and less in the stress state, and that you thereby become less susceptible to the impact of ongoing micro stress doses.

Tapping into your brain's plasticity

As we have seen, the brain has what we call 'neuroplasticity' - its architecture can be shaped and changed by our experiences. If, as a result of our experiences, we have an SNS bias, this can lead to us being more susceptible to the negative impacts of stress and more readily stressed when additional stressors are experienced. It may also mean that we perceive threat in our environment when, in fact, there is none. We have seen how repeated exposure to events, situations or interactions that evoke a stress response in us can put us into a stress state more and more frequently with the result that stress becomes our default state. We have seen how this can have long-term negative impacts on our health and wellbeing.

However, the neuroplasticity of our brains can also help us to change our current state of health and improve our wellbeing: just as our brain architecture can be modified by repeated experiences of stress, so too can it be modified by our ongoing, sustained experience of positive, regulating actions, situations and interactions. We can do this by providing our brains and bodies with frequent opportunities for experiences that put us into our thrive state. The more positive, regulating experiences we engage in, the more our brain will become used to being in the 'thrive' state, so much so that this then becomes our default state. Occasional stresses become occasional once more, and these can be useful, such as when cortisol is released to help us focus in a job interview or in an exam.



For the remainder of this resource, we will look at a variety of simple practices and activities that you can include in your daily or weekly routines so as to improve your health and wellbeing and to help reset your nervous system to being in a thrive state more often.

We know that, as a carer, adding anything new into your day can feel daunting, overwhelming and quite frankly impossible. For this reason, we recommend that you think about starting with quite small changes that you can add into your day slowly and at a time that feels right. We suggest doing it this way because, as a carer, your needs are likely to have become secondary to those of the person you support. So the first thing we need to do is remember the 'oxygen mask' rule: you need to make sure that you are alright before you can begin to support someone else to be okay. We hope that, having read about stress and the impacts it can have on your mental and physical health, we have been able to convince you that, in order for you to be able to continue supporting another person in the long term, it is important for you to create some time and space for yourself. Adopting small changes in your daily and weekly routines can help you to improve your wellbeing and, thereby, the wellbeing of the person you care for.

On the whole, we know that carers are not brilliant at focussing on themselves - they're used to putting other people's needs before their own. This resource is all about you: it's about taking steps to recognise why you need to put yourself first so that you can reliably, consistently be your most regulated self and therefore the best carer you can be for the person you care for. Putting yourself first or seeing things this way may feel uncomfortable at first, but if you adopt some or many of the strategies in this resource, you should begin to feel better than you do today and to enjoy improved mental and physical health in the future.

Recognising what stress feels like in your body

When we feel stressed, we react physiologically. We may not always recognise the sensations of stress in our bodies nor recognise how the experience of stress can skew our way of being in the world. When we are stressed, we may experience some or all of the following:

- Rapid heart rate
- Altered breathing
- Feeling nauseous
- Tightening of our muscles
- Dry mouth
- Restlessness
- Difficulty thinking straight
- Feeling panicky or anxious
- Feeling unstable
- Being hypervigilant
- Feeling threatened.

These signals and sensations in your body give rise to a pervasive feeling that you are unsafe and under threat.

Once we recognise that we are becoming stressed, we can take steps to help reduce our bodily experience of stress and signal to our brain that we are, in fact, safe - steps such as deep breathing techniques which activate a PNS response. Prior to undertaking an activity or interaction that we are likely to find stressful, we can proactively regulate ourselves by sending safe, calm messages to our bodies. This might take the form of a walk in the fresh air, a hot bath, a bowl of porridge or choosing to wear a favourite garment or piece of jewellery. Activities of daily self-care such as these can regulate us proactively and so make the upcoming activity or interaction feel less daunting and more doable.

Creating new habits

For us as carers, the idea of creating new habits can be daunting, especially as many of us may feel like we don't have much room to manoeuvre because of our caring responsibilities. In this resource, we invite you to consider making small changes in your life that, over time, may have a positive impact on your physical and mental health and your wellbeing. Moreover, when added together, the small changes that you make may combine and add up to bigger changes in your life.

In creating this resource - in our own self-care, in our own lives - we have found time and again that small changes can have disproportionately large impacts. We would love for you to join us - gradually, consciously - in adding small changes into your life that support you to feel regulated and to feel as good as you can in the face of the constraints - some minor, some major - imposed by your caring responsibilities.

When we think about our habits, we tend to think about the bad habits we have, like pressing 'snooze' on the alarm clock when we know we really should get up, or forgetting to rinse the bath out. However, it's worth remembering that, at the same time, we have lots of good habits built into our day but they tend to be so routine we don't give them a second thought - habits like brushing your teeth, locking the front door, feeding the pets and so on.

We hope that there are some new habits or practices in this resource that you will enjoy incorporating into your everyday life, such as going for a walk, deep breathing, listening to your favourite music more often and so on. Cumulatively, these practices will support you to be in your thrive state more often and to stay there for longer. Over time, the idea is that feeling safe and regulated will become your default setting. Remember, doing a simple activity for as little as five minutes, three times a day, can have a positive impact (Chatterjee, 2019).



Top tips for starting new habits:

- start off simply – choose something easy that you are most likely to succeed at building into your day.
 - connect a new practice/habit to an existing one – for example, when you make yourself a hot drink in the morning, try doing a five minute stretching routine while the kettle boils
 - think about what time of the day you are most likely to succeed at a particular new practice/habit – for example, try doing some yoga before you get dressed in the morning or after putting your PJs on at bedtime
 - set your home up to help you with your new practices/habits – for example, have a step in the bathroom so you can do step exercises while you brush your teeth, or if you want to take five minutes relaxation for yourself, take yourself off to a room where there is no technology available (smart phone/iPad/TV)
 - be kind to yourself - if you praise yourself when you have managed to do a new practice/habit and reflect positively on it, you are more likely to do it again in the future
- (adapted from Chatterjee, 2019).

Having a sense of purpose

Being a carer can be incredibly challenging, but it can also, at times, be very enriching. It can be difficult, however, for us to see the amazing difference we are making, both to the individual we care for and to wider society. The caring role is often overlooked, despite being one of the most important roles played in our society. Taking time to recognise the importance of our caring role and the significant contribution we make - both to the individual and to our community - can help to give us a greater sense of purpose in our lives. Of course, a sense of purpose can come from all sorts of things we do and roles we fulfil, but for some of us our caring role may be so all-consuming that, for some time now, it has felt like the sole purpose in our lives.

Recognising and holding onto a sense of purpose in our caring role may help us, as carers, to feel regulated, and as such can promote positive feelings and improved mental health. However, the caring role is, at times, beset by tasks and situations that frustrate and overwhelm us. Trying to find the positive in some situations can be very difficult. So that we can spend more time in a thrive rather than a stress state, it can sometimes help to spend time reflecting on how we view our situation, how we present it to ourselves. When changes to the external situation are not possible, we may need to effect change from within.

To do this, we can use strategies such as reframing, saying affirmations and doing gratitude practices which can help us reflect. These small steps can have a significant impact on how you view your situation and, when done regularly and habitually, can change the way you view and think about your situation. As first steps in self-care, reframing, saying affirmations and doing gratitude practices are recommended because of the potential benefits they bring and because they are quick and easy to incorporate into your daily routine.

Reframing: looking at things differently

Reframing the way we view and think about our situation can help in managing how we feel about our caring role. Sometimes, when we are finding things difficult, we ruminate and replay things over and over again in our minds. In such situations, it is important for us to consciously reflect on why it is that the things we do in our caring role actually matter. For example, after a difficult phone conversation to rearrange an appointment, you may feel stressed out and frustrated and so dwell on the phone conversation. This, needless to say, will make you feel even more stressed out and frustrated. Alternatively, you can choose to reframe the experience, to present it to yourself differently: you can say to yourself, 'good on me for sticking with that conversation and holding out until I'd got the appointment rescheduled' or 'that was a difficult conversation, I'm so glad I was able to rearrange the appointment, the new time is much more convenient'.

Reframing a situation in this way can help us to manage stressful situations in a way that returns to us a sense of control and agency. At the same time, reframing allows us to recognise success when we might otherwise overlook it.

Affirmations: training your brain

An affirmation is a short, positive statement that you say regularly. Saying an affirmation repeatedly can help to change both your mindset and your relationship with the world around you (see Chatterjee 2018a). An affirmation needs to be positive and a statement that relates to the present rather than to future aspirations. For example, 'I am feeling relaxed and I am staying calm' or 'It is ok for me not to worry about that now.'



Choosing an affirmation that will help you can be difficult. Chatterjee (2018a) suggests that you can choose a characteristic about yourself that you perceive as negative and 'flip it on its head' for example, if you consider yourself 'highly strung' you can choose an affirmation such as 'I am calm and stress-free'. For those of us who struggle to be away from the person we care for, we can include them in the affirmation: 'My partner is safe. I can relax and take time for myself', 'I can fulfil my caring role and still have time for myself' or 'Practising self-care makes me a good carer'.

You can use affirmations to help you feel differently, for example, 'I feel full of energy', 'I am ready for the day', 'I choose to be happy'. When you choose affirmations such as these, you say them aloud and imagine yourself feeling that way.

It is recommended that you repeat the affirmation multiple times for a couple of minutes, ideally in the morning but where possible throughout the day. On those mornings when you really don't feel like saying your affirmation, it may be that saying your affirmation is something that might help you to turn the morning round. We recommend writing the affirmations down to remember them. You may also like to use different affirmations at different times and to revisit ones you have used before.

Gratitude: bringing the focus onto the positive

When we think about things that are negative or about stressful events in the past, we may reactivate the stress response in our body. At the same time, we may activate our emotional brain and thereby become focused on threats whilst failing to notice the positives. With our emotional brain leading, we find it more difficult to think things through using logic and reasoning. Sometimes, in order to help our brains notice and value the positive aspects in our lives, we need to actively seek out and identify the positives each day.

One way of practising gratitude is to write a gratitude journal each evening before bed. You can write a minimum of three good things that happened that day, or more if you feel inclined. It can be simple things such as, 'I really enjoyed my breakfast', 'my partner hugged me in the kitchen', 'the way the dog greeted me', 'talking to mum on the phone', 'watching the raindrops roll down the window pane'.

Taking time out

Some of you may worry about the safety of the person you care for if you are not physically or emotionally there for them all the time. You may need to ask for practical help with keeping the person you care for safe. One way to do this is by seeking support from social services. A Carer's Assessment will support you to access any help and respite support to which you are entitled. Once you know that the person you care for is being looked after and is physically safe, you need to give yourself permission to have time away from them and to not feel guilty doing so. You may even need to say the affirmation to yourself, 'I am a better carer because I have time to myself, I do not feel guilty.' It has been found that saying an affirmation can help us to embody and act on its content.

Finding the time: how can I take time out when there is simply too much to do?

Carers who can't find the time to take time out for themselves are, not surprisingly, the ones who need it the most. Some of you may feel your day is so full that you are not able to take any time out from the ongoing round of daily tasks. As bizarre as it sounds, scheduling every minute of the day is one way to claim back some time in a really busy life (for example, 7am - wake up, 7am to 7.25am - get washed and dressed, and so on). The most important thing to do when scheduling is to actually schedule time out! Initially, you may only manage to put in a 15-minute break in the morning and one in the afternoon. However, over time you may find that you manage to fit in more breaks as you become more efficient over the course of your day.

It has been shown that even short periods of time out can have health and wellbeing benefits (Fredrickson, 2001). Try not to spend that 15 minutes on a screen as screens activate your brain and are often linked to a source of stress such as social media, news bulletins or work emails.

What would I do with my 'me' time?

For some of us, especially those who have been caring for a long time, knowing what to do with 'me' time is surprisingly difficult! Some people may instantly know what would make them happy or relaxed - for some, it will be quiet, still time, for others it may be 'doing'/active time, not things you have to do but things you enjoy and want to do. Try building a 'Feel-Good Menu' of activities. These questions may help you build your 'Feel-Good Menu':

- What would I like to spend more time doing?
- What makes me feel good physically?
- What makes me feel good mentally?
- Who do I want to spend more time with?

Ideas for 15-minute feel-good activities might include:

- Lye on the sofa with a good book
- Listen to music
- Draw
- Do some gardening
- Have a bath
- Go for a walk
- Sit in café and having a drink and a piece of cake
- Do some cooking
- Sit in the park and people-watch
- Move your body to music (you don't have to dance, just move as you want)
- Sing
- Write a letter
- Write a journal
- Try a meditation app such as Calm or Headspace
- Knit/embroider/crochet
- Have a cup of tea in the garden
- Listen to the radio
- Do a mindfulness exercise or mindful colouring in



My days are unpredictable because the person I care for needs me all the time which means that I can't plan anything

Some of us may not have support in place that enables us to take some time out from our caring role. For some, the needs of the person we care for may vary so much that planning respite for ourselves can feel like an impossible task. To get some 'me' time, we need to be creative. It may be that we need to take time out in our homes and within the context of our caring relationships. We may need to find ways of enjoying short, intermittent spells of calm throughout our caring day.

Chatterjee (2018a: 64) recommends 'Zoning In' - creating short pockets of regular activities in your day, ideally as part of your morning routine (although this can be difficult for those of us who are woken up in the night by the person we support). It might be ten minutes to make a cup of coffee and sit by an open window, or perhaps ten minutes of breathing exercises on the back doorstep (weather permitting!). Following brief routines like these at roughly the same time each day signals to our body that we are safe and in control, helping us to shift into the thrive state.

If the person you care for wakes up at the same time each day, you could wake up 15 minutes earlier and have time to yourself before your day starts. For those of us with jobs, it may mean leaving for work 15 minutes earlier for work and spending that time doing a calming activity such as listening to a meditation app or taking a different route to work that lets you walk a lap or two of your local park. This kind of 'zoning in' routine will set you up for your day and can also help you to refocus over the course of your day.

Chatterjee (2018a) suggests Three M's for zoning in in the morning:

- Mindfulness (breathing, being in nature or meditation)
- Movement (moving your body physically e.g. stretching, dancing, pilates or yoga)
- Mindset (gratitude practices and affirmations).

He also recommends having a Golden Hour each morning, when your mobile phone remains off, allowing your thoughts to wander free for a bit longer and reducing the risk of starting the day with unwanted micro stress doses.

Embracing time alone

Being alone can give you time to think, and often this can be a good thing. Some of us, though, may find ourselves becoming fixated and overthinking things, in particular the stressors we are experiencing in our lives. This can make time alone counter-productive, and we may find we are better off doing some kind of activity that engages our attention or that relaxes us. It may be that you are the kind of person who is better off doing an activity to relax, rather than being left alone with your thoughts.

Doing something you love

Even if it is only for 5 or 10 minutes a day, find the time to do something you love. That may sound easier than it is, especially if you have been dedicated to caring for someone for a long time and have somehow lost touch with the things you love. Try different activities, you may surprise yourself! Finding out what you do actually enjoy and how you can fit it into your life is all part of the process. Give it time and, soon enough, you will find something that you love and a way of fitting it into your life.

I only ever get a couple of minutes to do something before I am needed again, it's hard to do something creative when there are constant interruptions!

Ideas for activities that you can pick up and put down - activities that don't need any setting up - include:

- Sewing/embroidery
- Knitting
- Quilting
- Watercolour painting
- Sketching
- Playing a musical instrument
- Singing
- Dancing
- Crafting (eg making cards, doing origami, wood carving)
- Doing a puzzle (Sudoku, Suguru, a crossword...)
- Reading
- Mindfulness colouring books
- Creative writing

When we are engrossed in making something, we enter a 'flow' state where our worries and what is going on around us somehow recede into the background. In a 'flow' state, we are wholly absorbed in the process of creating. This 'flow' state nourishes the 'rational brain' and reduces our stress levels (Chatterjee, 2018a).

Flow is made up of six core components:

Complete concentration on the task in hand. Our thoughts and actions become one.

- Our sense of self somehow dissolves - the ego is quietened
- Our perception of time changes
- Any sense of anxious struggle disappears
- Our sense of control increases - the task in hand provides immediate feedback which in turn promotes psychological immersion
- The task in hand becomes a pleasurable experience in and of itself.

(adapted from Chatterjee, 2022)

The way we do things

Sometimes, we go into automatic mode, just trying to get things done, such that we lose some of the joy or ritual connected to the tasks we are engaged in. Most of the time, we feel we are working against the clock and we just need to get things done. This way of doing things, although often efficient, can also feel stressful or devoid of meaning.

When we take an everyday task and allow ourselves to engage with it mindfully, we become more present in the moment and things take on greater meaning. There's a school of thought that says when we start paying attention to the small things, the big things start looking after themselves. Finding pleasure through mindful attention is a practice that you can follow throughout your day. It's a good idea, if this way of doing things is new to you, to start off small - try brewing yourself a cup of tea in an attentive, mindful way.



All sorts of activities can be done mindfully and with intent:

- Watering the plants
- Brewing a pot of tea
- Chopping vegetables
- Cooking
- Gardening
- Laying the table

But I don't know who I am anymore!

It can be difficult to maintain a sense of self when we are fully absorbed in caring for another person. As carers, we may grieve for who we were before we started caring. We may wonder what our lives might be like if we had been able to carry on with the life we had before.

In a full-time caring role, there may be very little scope, emotionally, to feel wholly yourself and fully able to reach your potential. This realisation can be very hard to accept and be okay with. For some of us, speaking to a therapist may help us to find a way to connect with ourselves, while for others this may seem too daunting. We may decide instead to use our respite time to do something where we are connected with and working alongside other people - we might volunteer for an hour or two at a food bank or listen to children read at primary school. Engaging with others, widening our social sphere, can help us to have a stronger sense of who we are.

Being kind can help you feel happier and healthier

Being a care-giver for another person is a great act of kindness and can be protective for us too, as acts of kindness cause the release of oxytocin (Hamilton, 2017). Oxytocin is the hormone released when we are hugging or cuddling someone, it's our 'connection' hormone that makes us feel warm and comfortable and connected to another person. We produce oxytocin when we are being kind to someone. Caring for and being kind to the person we care for can be difficult to keep up at times, but the kindness inherent in caring for another person can also provide us with the feel-good hormone oxytocin. Oxytocin can contribute towards protecting our cardiovascular system by bringing blood pressure down, and is also an antioxidant and anti-inflammatory.



Making extra efforts to connect with other people can help you to feel a greater sense of engagement with the world outside your home and beyond your caring relationship. Doing random acts of kindness, taking time to talk to the cashier in the supermarket, holding the door open for others - these are all examples of small acts of kindness that you can do that will give you a boost of oxytocin, your feel-good hormone. You can find lots more ideas here.

Touch

In this section we are going to consider the importance of touch. It is worth noting at this point that not everyone likes to be touched, for some people it can be painful and feel threatening. Touch also needs to be appropriate and consensual.

Our caring relationships often involve lots of touch, though often we are the giver of touch and may feel a loss when we do not receive touch in return. This can be a particularly acute feeling when our partner is the one we care for, there may now be a loss of intimate touch or the touch that we now give may be that of providing personal care rather than emotionally motivated touch.

A baby develops the sense of touch first when it is in the womb. Touch is significant for an infant's neural development and their connections with others. We are social beings and a lack of touch can have negative effects on our wellbeing and development. Affectionate touch can reduce feelings of social exclusion (University College London, 2017).

Human touch has a positive impact on our physical well being, it slows down our heart rate, lowers blood pressure and reduces cortisol levels. A lack of touch is a stress factor for us and can put us in a stress state (Chatterjee, 2018a). Conversely, pleasant, affectionate touch lowers our stress responses and can put us in a thrive state. Touch causes the release of serotonin (the 'feel-good chemical'), oxytocin (the 'cuddle chemical') and endogenous opioids that improve mood, decrease pain and lower anxiety.

When we are caring for a loved one, we may find that, over time, we have somehow stopped giving affectionate touch and the only touch we do use is that entailed in care-giving tasks. Although the person you are caring for may not be able to initiate affectionate touch, if they like to be touched, you can make a conscious effort to hold their hand more, to sit close to one another, to stroke their arm or stroke the top of their back. You may find the giving of affectionate touch means that the person you care for is able to respond in kind instinctively. If the person you care for is not able to initiate affectionate touch with you, the kind act of sitting together and giving affectionate touch to your loved one may lead to the release of oxytocin for both of you.

Chatterjee (2018a) suggests keeping a touch diary to discover just how many times you give and receive gentle, warm, affectionate human touch. He suggests counting up the number of times at the end of week one, then trying to double the number in week two and, by the end of the month, tripling it. When we give warm affectionate touch, for example by hugging people, touching them on the arm or on the back it brings a closeness and warmth back into relationships.

If you tend not to receive affectionate touch from a loved one, you could:

- Consider having a massage
- Applying body cream or moisturiser to your skin
- Stroke a pet (we benefit from touching our pets, too)
- Cosy up on the sofa with your dog or cat.

Angela:

I remember so clearly one of the first times I had a couple of hours of respite, I didn't know what to do with myself. I was so out of touch with who I was and what I needed that I just took myself into town as an automatic habit of 'getting out'. And that is how I found myself wandering round a pine furniture shop, stroking the furniture and getting close enough to breathe in the glorious pinewood scent of the tables and cabinets. I must have looked very strange, but it was so unexpectedly what I needed that I didn't care. Stroking furniture still brings a smile to my face.

Connecting with others: intimacy

The pressures of modern life exert a significant impact on our relationships. Demands on all of us have increased and there is a risk that we become more distant from our partners. Research suggests that couples are having less sexual contact with each other (Chatterjee, 2018a). In addition to the pressures many of us find ourselves under, providing care for another person can be tiring and all consuming. Many of us find that, despite our best intentions, our intimate relationships can become neglected.

Laura:

The demands of caring have put strains on my relationship with my husband. For many years he commuted to London five days a week so I did all of the caring (for our daughter) and parenting (for both children) and did ALL of the appointments, meetings, advocacy, paperwork, research into education and therapies, going on courses, finding out about and implementing strategies, finding and employing PAs and plan all the family day-to-day activities and holidays - it can feel like a full-time job on top of trying to maintain some sense of self with part-time work. Our lives have felt incredibly separate and his disinterest in being involved at any level, or showing interest, has saddened me. Since the end of the pandemic, my husband has been able to work from home some of the time – this has meant he has been able to take on some of the caring (I requested this) which is great, but we do find ourselves 'tag-teaming' our daughter – the caring role is so intense that we get out of the habit of making time for each other and our lives can feel quite separate unless a concerted effort is made. What we have in common is our daughter.

Intimacy does not have to mean sex. Intimacy is the glue that binds us together and brings us joy. Intimacy is trusting each other and being alongside each other, feeling that your partner 'has your back'. Intimacy is caring deeply for one another, it's being able to share your thoughts and fears. Intimacy can be mindfully spending time together, sharing a cup of tea with all distractions removed. It can simply be holding hands on the sofa, having a nap together or going for a walk together.

Sometimes intimate moments may lead to sex but it is important that neither of you feels pressure to make that happen. When you are caring intensively for someone else, you and your partner may both be feeling the pressure of that care responsibility and it may be that you need to schedule time simply to be together. If this feels somehow unromantic, it is important to remember that having uninterrupted time together creates opportunities for intimate togetherness and the benefits that brings to your own happiness, health and wellbeing. It can promote your physical and psychological wellbeing and thereby support you to continue providing care as consistently and as effectively as possible.

Friendships

Becoming a carer can highlight to you who your good friends are and, sadly, sometimes we lose friends in the transition. When a life event happens to us that is so significant we have to take on the role of a carer, often some of our friends may not know how to support us with this transition, they may feel uncomfortable and feel they don't know what to say to you. People sometimes get scared of saying the wrong thing and end up not saying anything and, over time, friendships go by the wayside. This can be very painful. In the event, you may be surprised by which of your friends have managed to stay alongside you.

Some of you may have always been in a caring role and your friends may be better at understanding the impact that the caring role can have on your capacity to participate in social life. Others may have friends who find it difficult to accept that you are no longer there for them in the way you were before you became a carer.

Having a social network to support you can have a tremendous impact on your wellbeing, yet sadly many of us lack such a support network. The longer we have been feeling alone, the harder it can be for us to take steps to build a social group around us. groups.

If we are feeling ground down by our caring role, finding people who understand our situation can be very difficult. For this reason, many care-givers benefit from participating in carer support networks and attending peer support. Taking a leap to make new social connections when you are already juggling your caring responsibilities and possibly work as well can feel really overwhelming, so it may be an idea to take small steps initially and see what happens. Think about becoming a 'regular' – going regularly to the same café at the same time, doing a weekly class or joining a club such as a local book club. Over time, you will start seeing familiar faces and gradually you and they will start to say hello and build connections.

If a friendship is no longer nourishing for you, do not be afraid to disengage from the friendship when the time is right. Not all friendships are meant to last forever and, as your circumstances change, you may find you get what you need from newer, different friendships forged in your current circumstances.



Allies

Allies are invaluable when you are a care-giver. Allies may be found in the places where you hope to find them, such as in the form of your GP or social worker. You also come across unexpected allies, such as a neighbour who has walked the caring path before and can offer you some company on yours.

Angela:

It seems obvious, but looking for allies can be what brings them to you. So often I felt as if I had to manage everything on my own, a complex belief that

- 1. Nobody else could do it*
- 2. It was too difficult to explain to anyone else*
- 3. Everyone else had busy lives of their own, and*
- 4. A fear that I did not want to look as if I couldn't cope.*

Occasionally some of these beliefs were true, (people DO have busy lives of their own and sometimes it was the case that only I could do what needed to be done), but mostly these thoughts became a toxic barrier that stopped me from even looking for help.

Allies come in all shapes and sizes but the most important thing is to be able to recognise them in your life, and sometimes they just don't look like the image you may have of what you need. Desperate for some holiday activities for my daughter that would also give me an hour or two of respite, I enrolled her in a volunteer-based holiday scheme that had started up locally.

Not only was the scheme a godsend for the few weeks it operated, but the volunteer who was assigned to my daughter became a treasured family ally over the next twenty-plus years. And it was far from a one-way street. The meeting and sharing of our lives supported and enriched every member of both families and extended to shared holidays and appreciation for each other in our often difficult lives. People need to feel they are met and valued for who they are, not just what they do. That goes for us carers as well.



Social media

There is no question that there is peer support and companionship to be found on social media, for example in carer support groups. Support groups and forums can also be accessed 24 hours a day and some of us are awake caring when the rest of the world sleeps. However, beware of online platforms that are not supportive or that do not make you feel enriched after being on them. Some forums can quickly become negative, stress-provoking and sometimes unkind. Sometimes people respond unkindly to our posts, misconstruing what we meant to say or making judgments based on incomplete knowledge of the facts.

Connecting with people who matter to you

- Don't just leave a comment on people's media, reach out and arrange to meet in person and, if that is not possible, do a video call where you can see each other. Looking into each other's eyes and hearing each other's voice conveys so much more than typed words and emojis.
- Put actual dates to meet up in the diary, rather than just saying "let's meet up soon".
- Don't feel you have to pretend everything is okay - if it feels right, try being truthful with your friends. Sharing your stress can really help.
- If you haven't been in touch with a group of friends for a while, choose one you really care about and make a phone call. When you feel more confident, try phoning someone for a catch-up at least once a week, then try and make it twice a week or more often.
- If you can, meet up in town or at a country pub so that you are free from responsibilities. If you can't manage this, invite friends round to yours when the opportunity presents itself.
- Write good old-fashioned letters, everyone likes receiving a letter but we rarely do it nowadays. It can be therapeutic to write a letter and precious to receive one.

Offloading

As carers, one of the powerful releases we have is offloading to a friend or family member. Offloading our worries and concerns and sharing our frustrations has a powerful impact on our well-being. It's not always easy, though, as we may feel we are imposing on them or perhaps we don't see them often enough to be able to speak candidly. If there's nobody we can offload to, an alternative is to write a journal where we off-load our thoughts and 'unburden' ourselves. Sometimes this private offloading can actually be more honest and more real, it can be a powerful experience.

Linda:

If we know Nia is not in a good place, we always try to ensure there is someone on "stand-by" so we can have a break from her, even going outside and taking deep breaths can help. Once Nia is settled, I find it's important to offload, either by chatting to my best friend or by posting on a social media group for parents of children/adults with Down's Syndrome and autism. They seem to be the only people who get it and always respond with kindness and humour – laughter is a real tonic.

Offloading in a journal does not have to relate directly to your caring role, it can be freely depositing your thoughts and may include things such as, 'I mustn't forget the dog's medicine today, I like the sound of the rain on the window...'. It doesn't have to read well or even make sense, it is just you parking your thoughts.

Try doing a written 'offload' or 'brain dump' for five minutes every morning, you can write in a notebook or on your phone. Doing this daily can help you think more clearly and have a less anxious mind.

Thought releasing

Another way to get your thoughts out of your head is to have a clean sheet of paper, put a five-minute timer on and literally write whatever comes into your mind (a practice called free-writing). Afterwards, you can shred or recycle your thoughts or keep them safe in a drawer. Some people keep a free-writing journal. If you decide to give it a go, don't hold back, just let the thoughts flow through your pen with no judgement – there is no 'wrong' or 'right' in free-writing.

Free-writing can be difficult, especially getting started, so sometimes a bit of structure can help us to focus our thoughts. You could try writing down:

1. One thing you are anxious about today
2. One practical thing you can do to prepare for it or to prevent it
3. One reason why it's probably not going to be as bad as you fear
4. One reason why you know you can handle it
5. One upside of the situation.

(adapted from Chatterjee, 2019)

Rest and relaxation

Rest and relaxation can help to balance out the stresses of life. Your initial response to this suggestion might very well be, 'Relax? Where will I find the time?!'. For us as carers, it can be incredibly difficult to find the time to relax. Or, if we find some time to relax, it can be difficult to relax without being beset by feelings of guilt. However, relaxing is essential in reducing stress and offsetting its longer term impacts. Consistently claiming opportunities to relax, even if they are small breaks lasting only a few minutes, can, over time, begin to reset your nervous system away from a stress state bias towards a thrive state. Indeed, just fifteen minutes of 'me-time' a day can help normalise cortisol levels 'Me-time' (Chatterjee, 2018: 34).

Relaxing can bring a range of benefits to us as carers:

- Weight loss
- Improved resilience
- Reduced feelings of stress
- Improved ability to cope
- More balanced outlook
- Less road rage
- Improved ability to sleep
- More restorative sleep
- Better concentration.



Digital detox

Smartphones mean that we are contactable pretty much any time of the day or night and, sometimes without our realising it, our smartphones can become a source of stress. For many of us, smartphones have made it more difficult to 'switch off'. Many of us think that by surfing the net, we're having time out, but this kind of phone use can be highly activating for our brains in terms of the light emitted but also the content we view, which itself can be activating. Our smartphones being so close to hand throughout the day means we tend to check them regularly. The new emails that we see when we check our phones make our 'things to do' list even longer. Sometimes it feels as though the more you look at your smartphone, the more you become addicted to looking at it. All of us who use smartphones tend to compare our lives to the lives of our friends and contacts that we see paraded in posts, updates and images on social media, and our instinct is to judge ourselves as falling short of some sort of norm that actually doesn't exist. We compare the lived reality of our own lives to the idealised versions we see on social media.

Here are some tips for reducing the negative impacts of smartphone use in our daily lives:

- See if you can take smartphones and technology out of mealtimes
- Check emails once a day at a time when you are able to respond - that way they won't add to your to-do list
- Restrict the hours of the day when you use your smartphone, eg turn your phone off between 6pm and 6am
- Turn off notifications for Whatsapp and Facebook Messenger groups that have the potential to cause you stress
- Turn off automatic syncing
- Have a separate email account for friends and family so you see only the emails you want to see
- Keep your smartphone out of sight if you are not actively using it
- Put your smartphone in 'grayscale' so it is less engaging
- Take news apps off your smartphone
- Track your usage.

Being out in nature

We are hard-wired to thrive in natural environments but modern life is increasingly separate from the natural world. Being out in nature brings all sorts of benefits:

- Lowers stress levels
- Reduces depression
- Improves mental focus
- Boosts the immune system
- Increases endurance
- Reduces tiredness
- Reduces the chance of disease.

(adapted from Chatterjee, 2019)

Any time in nature is good for you even if you are doing something else at the same time such as having a cup of tea in the garden, on a balcony or even by an open window enjoying the fresh air and listening to the sounds of nature.

Suzy:

Pretty much all of the things we enjoy involve us going out and about in the fresh air, connecting, just us – for example, do a day trip to a favourite place, get in the car and do a long walk in the countryside taking a flask and a picnic, litter-picking round the town, bramble cutting in the parks and nearby fields, taking abandoned trolleys back to shops, putting bins back in people's driveways, plan a weekend ride on the tandem, take a box of paints and a cardboard box in the garden and make a mess. I am totally there for Kip, and following his lead and pace, but tell Kip the things I want to do and build them into the day. When we do these things, everything is good and calm and fun.

Here are some ideas for connecting with the natural world:

After breakfast each morning, take a photo of a tree/your garden/the view from your window

Plant some bulbs in your garden or in a window box

Spend time feeling the wind, sun or rain on your face

Have some indoor plants in your living room

If it's nice out, have you window open so you can hear the birds singing

Put photographs and images of nature in your home

If it's difficult for you to get outside in the natural world, there are benefits in listening to recordings of the sounds of nature such as waves crashing on the shore, whale song, birdsong or woodland sounds. You can readily find such recordings on, for example, Spotify, iTunes or Youtube.

Linda:

Nia loves being outside in nature. Our happy times are on a summer evening after school, walking across the fields, seeing the animals and waving and laughing at our shadows. Not quite the same on a cold wet winters' day when it's dark by 4.30, but we do try to get out as often as we can.



Breathing

Breathing techniques can have a powerful impact on your body as well as your mental state. Breathing is a secret tool that we have with us all of the time - it can be done anywhere and others can't even tell you are doing it any differently to normal. It's like powerful, portable first aid!

Breathing plays a significant role in supporting our regulation. People often say 'take a deep breath' when someone is overwhelmed, and this tends to help but most of us don't know why.

Our breathing patterns send signals to our brain. For example, when we are anxious or angry our breathing is shallower and more rapid, signalling to our brain that we are in a stressful situation and potentially unsafe. If we consciously breathe slowly, deeply and in a relaxed way, we signal to our brain that we are safe and everything is okay. In breathing this way, we are activating the parasympathetic nervous system and its associated 'thrive state'. Breathing techniques can help us stay more regulated and promote improved physical and mental health.

Breathing is central to the practice of meditation, but many people, especially those who are habitually in a stress state, find meditation difficult because it is not easy to rein in their thoughts. For some people, trying some straightforward breathing techniques is a more doable first step towards mediation. Focussing our attention on the breath can help to dispel those invasive thoughts that may disrupt the stillness we seek in meditation.

Breathing exercises can be done wherever you feel comfortable. For many of us, it is easiest to lie on the floor as this offers plenty of bodily support that helps us to feel grounded. For others, it may work best lying in bed, sitting on a chair or when we are out walking. Try lying on the floor with one hand on your stomach and one on your chest. You'll know when you are breathing from your diaphragm when your stomach rises and falls rather than your chest. Youtube has lots of videos on how to do this (it's called diaphragmatic breathing).

Angela:

My daughter's disabilities included breathing abnormalities. Sometimes when she was very distressed, breath-holding and throwing herself around, I learned to breathe gently onto her face. Part of the reason for this was to increase the carbon dioxide she was breathing. It's the same reason people who are panicking can be helped to regulate their breathing by holding a paper bag over their mouth and nose as they breathe. But it also gave us a chance to synchronise our breathing and that was another way to gradually calm her down. The fact is, we are designed to co-regulate and it is a beautiful feeling to rest together, breathing quietly in sync. Now, if I am feeling a growing sense of overwhelm, I take a deep breath. It slows me down and brings me back into the present moment. Anything that uses the breath in a positive way can make a big difference.

A popular breathing practice that is easy to envisage and get the hang of is Box Breathing. Box breathing is when you breathe in (through your nostrils) for three seconds, hold your breath for four seconds, breath out for five seconds, then hold for six seconds. It is the longer out-breath that activates the parasympathetic thrive state (rest and digest).

Meditation

Meditation doesn't have to mean sitting still with your legs crossed emptying your mind of thoughts. Meditation, like mindfulness, is about finding stillness. Meditation can be walking with awareness, listening to your favourite song and focussing on different elements of the music in turn, doing Tai Chi - it can be anything that is done consciously and mindfully. If you are interested in giving meditation a go, there are apps such as Calm and Headspace that offer an easy way in.

Eating

Nutrition has a direct impact on brain function, indeed there is evidence that the food we eat can have a positive or negative impact on our physical and mental wellbeing. Our gut directly communicates with our brain via the 'gut-brain axis'. Food is about more than energy and feeling sated, it is also about providing us with the right nutrients and 'good' gut bacteria. Highly processed food can have a detrimental effect on our good gut bacteria. As carers, we are often short of time and, for many of us, processed food has our go-to meal option. It may be daunting to consider making a shift back to more home-cooked food, but if you can take steps in that direction then, over time, your wellbeing will benefit.

Here are some initial ideas for starting a move away from unprocessed foods:

- Smoothies - making fresh fruit smoothies with a rainbow of colours will give you a boost. Blueberries, though expensive, are a great brain-nourishing ingredient. You can also include things like nuts (walnuts that are rich in omega 3 oils), spinach and avocado.
- Raw carrot dipped in hummus, fresh avocado smash or a yoghurt-based dip like tzatziki
- Boiling up vegetables and blitzing them in a blender to make delicious soups (you can buy soup blenders that do the whole thing for you)
- Eating a rainbow (as many different coloured vegetables as possible in a week (Chatterjee has an excellent [chart](#) for this challenge).

Movement

One of the simplest ways to add movement into your life is to walk more. A target of 10,000 steps a day may feel daunting at first, so it's a good idea to see what a normal day's walking is for you and then build up slowly, adding 500 or 1,000 more steps, depending on what feels doable (1,000 steps is roughly ten minutes' walking). You can measure your steps with a sports watch, an app on your phone or a pedometer. Walking has numerous health benefits and can improve your mental wellbeing and quality of life.

Ideas for walking more:

- Walk up the stairs instead of taking the lift or escalator
- Park further away from the shops so you have to walk more
- Get off the bus or tube a stop earlier and walk the rest
- Walk to get everyday items from local shops rather than doing a weekly supermarket shop
- Walk rather than drive to places when you can, such as your journey to work or doing the school run
- Walk in your local park or countryside near you
- Meet up with a friend for a walk rather than a coffee.

Starting your day with a morning walk can set you up in a calmer state of mind for the rest of the day.



Getting fit:

For those of us not able to leave home to exercise, take a look at Dr Chatterjee's home workouts on youtube or his website, www.drchatterjee.com such as his [Five Minute workout](#) or his [clockwork out](#).

Sleep

Suzy:

Sleep seems to be the most important thing for my well-being and so in turn for Kip's well-being – the ritual of having a valerian tea each night and reading a book before sleep helps, as does listening to a Benjamin Zephaniah podcast talking about breathing that I randomly found one day. Even doing all of this doesn't always work, sometimes I just have too much to process from the day or things that worry me keeping me awake. When that happens, I admit defeat and come downstairs, sit with the (sleeping) dog, look through some photo books and even do some middle-of-the-night cooking. About an hour later, I'm tired enough to go back to bed.

Caring for others can often mean that you miss out on sleep. For many care-givers, an unbroken eight hours' sleep is difficult to imagine. Even when the person we care for is in overnight respite, we may still find sleep hard to come by. For all of us, a longer sleep makes us feel better, but many care-givers have broken nights because the person we care for needs us or because our own stress and anxiety keep us awake. Not surprisingly, long-term lack of sleep can have a negative impact on our health and wellbeing.

Ideas to improve your quality of sleep:

- If you can, try having your bedroom completely dark
- See if not having a TV or any electronic devices in your bedroom makes a difference
- In the hours before sleep, dim the lights in your home if you can
- Avoid using your smartphone for the last couple of hours before bed, but if this is tricky, try wearing amber glasses to reduce exposure to the blue light emitted by your device as it is alerting for your mind
- Turn the TV off 30 minutes before you go to bed
- Before bed, avoid TV programmes that evoke the stress response such as horror films, dramas and thrillers
- Spending time outdoors in the morning light helps our body with its natural rhythms
- Create a bedtime routine for yourself, you could try setting an alarm to remind yourself to start getting ready for bed
- Napping (micro sleeps) can feel like a luxury when there are so many things to do, but having a nap (whether it's five minutes or two hours) can have a restorative value yet not affect your night's sleep.

How can I improve my sleep when my nights are frequently interrupted by my caring responsibilities?

For those of us who have to get up in the night to provide care, getting eight hours of unbroken sleep is always going to be tricky. Nick Littlehales is a sleep coach who has turned the myth of the eight-hour sleep on its head (Littlehales, 2016). He proposes that we should not worry about having eight hours of unbroken sleep and should instead think of sleep in ninety-minute cycles. This is because, under clinical conditions, it takes ninety minutes to go through the stages of sleep that constitute a sleep cycle (Littlehales, 2016: 26).

If we think of our sleep in terms of 'cycles' rather than 'hours', we enjoy greater flexibility and reduced anxiety in terms of the quality of our sleep. Thinking in terms of the number of sleep cycles we get in a week rather than the number of hours sleep we get gives us more flexibility and agency - we can reframe 'last night I had a bad night's sleep' as 'today I need to have a ninety-minute nap'. It can also give us permission to 'claim' those additional cycles and catch up on sleep in the day without feeling guilty about it. For the average person, 35 cycles is ideal while 28 to 30 is okay (Littlehales, 2016: 36).

Angela:
Not sleeping properly for 36 years is an achievement I never expected to be part of. Sometimes I worry about what effect it is having on my overall health, but this was an aspect of caring that was beyond my control. I am like a Truffle Dog, sniffing out sleep whenever I can. My mantra is, "Don't beat myself up about not sleeping enough"! And if I do start beating myself up about my failure to implement perfect self-care habits... "Don't beat myself up about beating myself up"!

Siobhan:

I think I'm in a slightly different position in that I've come to caring for Rupert from a place of being so ill myself. Over years and years, before Rupert, I've had to develop my own strategies for getting through the day, for getting through the next hour, the next half-hour, for not being in the world in the same way that most people are, for loss and grief, and all of those things. So I feel sometimes I'm sort of... even within the world that we're in, I feel slightly different. I think if I'd come to this from a busy life in London, you know, at work and all other factors being great and equal and fine, I think it would have been a huge, huge smack in the face and learning curve. But I think I'm, bizarrely, better equipped tools-wise and strategies-wise to cope. But that said, I don't cope all the time, by any means. I get overwhelmed, massively, I get exhausted, and a lot of that is linked to sleep. So I have a massive thing where, if I had the energy, ironically, and I had the resources, I would like to put together some form of work where sleep for parent-carers becomes the utter... almost like a prescription, like a medical prescription, because I feel so strongly that you're just not able to cope on such difficult levels of sleep - sleep deprivation, lack of sleep quality - and that affects your caring. So above all, if, in every single social care, medical care, decision, resource allocation, sleep is put at the top. So, with everything else, how many nights a week does that parent get uninterrupted sleep of more than six hours? So I think one of the strategies for us is rest, it's a difficult thing to do, I can only ever rest a bit once Rupert's at school. For me, it's complex because of having ME, so rest is a really difficult thing, but I think for most parent-carers, those are the strategies - learning to rest, taking it day-by-day, sometimes taking it hour-by-hour.

Here are some ideas for improving your sleep:

Count your sleep in ninety-minute cycles rather than hours

Aim for 28 to 30 cycles in a week, ideally 35

If you have a broken night and missed one or more cycles, do not feel bad about catching up on them the following day

If you had a broken night and a friend offers to help you for a bit or if you have respite, ask for long enough for a ninety-minute cycle of sleep

There will always be times when sleep is more important than the washing up!

If you like to drink caffeinated drinks, try to have your last one before noon.

If things start to feel too much

As a care-giver, we often experience high levels of stress for extended periods of time. We may start to struggle and to feel like it is all getting too much for us to manage. Ideally, seek support early on, before things feel too much to manage. You are not alone in finding a caring role difficult talking to others can help. Alongside that going GP or social worker is a good place to start and they may be able to signpost you to practical and psychological support. There are also helpline that you can contact any time of the day or night (see below). If there is immediate danger to life, call 999 straightaway.

[Shout](#) offer a texting support service 24/7 across the UK

[C.A.L.L.](#) is a 24/7 freephone helpline and texting service available in Wales

[Samaritans](#) a 24/7 freephone helpline across the UK



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About Autism Wellbeing CIC

Autism Wellbeing CIC is a not-for-profit social enterprise based in Carmarthenshire. We are a team of professionals working collaboratively with autistic individuals and their families. We recognise that life can be complex and that individuals and families often have to overcome barriers in order to access the information and support services they need and to which they are entitled. For this reason, we work closely with and for autistic people, remaining alongside them as partners on their journey.

The Autism Wellbeing team includes highly skilled professionals with specialisms in autism, sensory processing, education and psychology. We positively value neurodiversity and recognise the benefits it brings to our team. Amongst Autism Wellbeing's directors, we have lived experience of autism, dyslexia, ADHD, dyspraxia and sensory impairment.

We have co-produced a range of services that combine our expertise with that of our partners – autistic individuals, their families and carers and the professionals who support them. None of our services requires the person to have a diagnosis of autism. You can find out more about us on our website: www.autismwellbeing.org.uk

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