

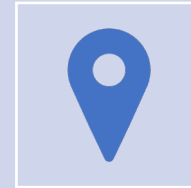


Adventist Special Needs Association

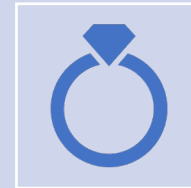
Do Carers Matter?

Sophia Nicholls M.Sc.,
M.Ed.

ASNA CEO



17th May 2022



30th Wedding
Anniversary



- Matthew & CJ Nicholls
- Matthew born with severe Learning and blind
- Developed sensory processing disorder
- Many other challenges



I am often asked to describe the experience of raising a child with a disability – to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this.....

When you're going to have a baby, it's like planning a fabulous vacation trip – to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The flight attendant comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine, and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

Welcome to Holland

- Unexpected
- Stages to Acceptance
- Lonely journey
- 5 stages to Acceptance ©
 - Anger
 - Anxiety
 - Awareness
 - Acknowledgment
 - Acceptance
- Celebrating the Joys of Holland

Biblical instructions for Carers

1 Peter 5:7 says “Cast all your anxiety on him because he cares for us”. Just throw it on him, and let him carry your burdens.

There is nothing we are going through that we cannot cast on the Lord.

1 Peter 5:7

- Peter wanted them to know that no matter what you are going through, all of your worries and anxieties can be thrown on the Lord, because he cares for us.

Psalms 55:22

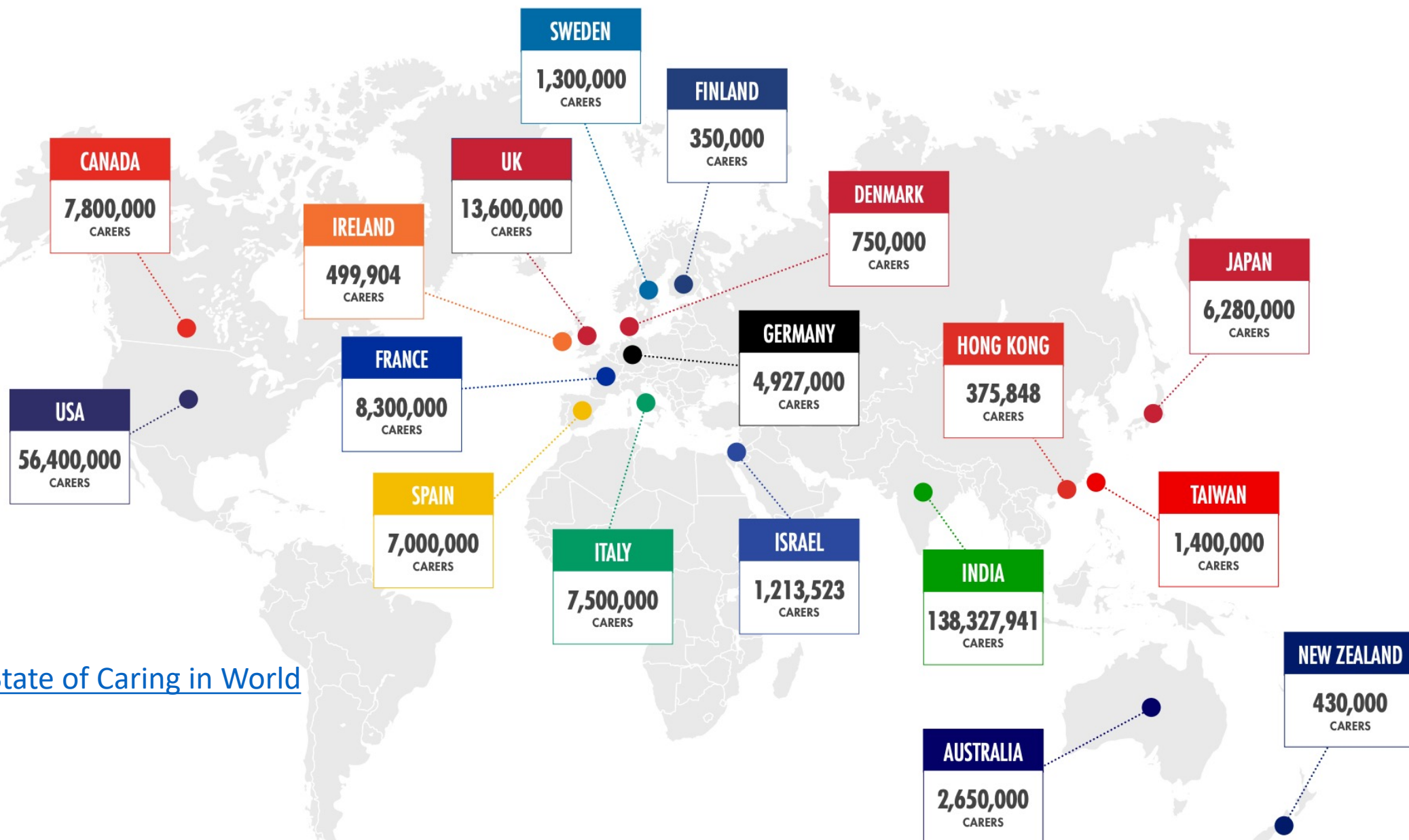
- David encouraged the same type of commitment in Psalm 55:22 when he said, “Cast thy burden upon the Lord, and He shall sustain thee: He shall never suffer the righteous to be moved.”

What is a Carer or Care - Giver

A carer is anyone (including children -Young Carers) who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support.

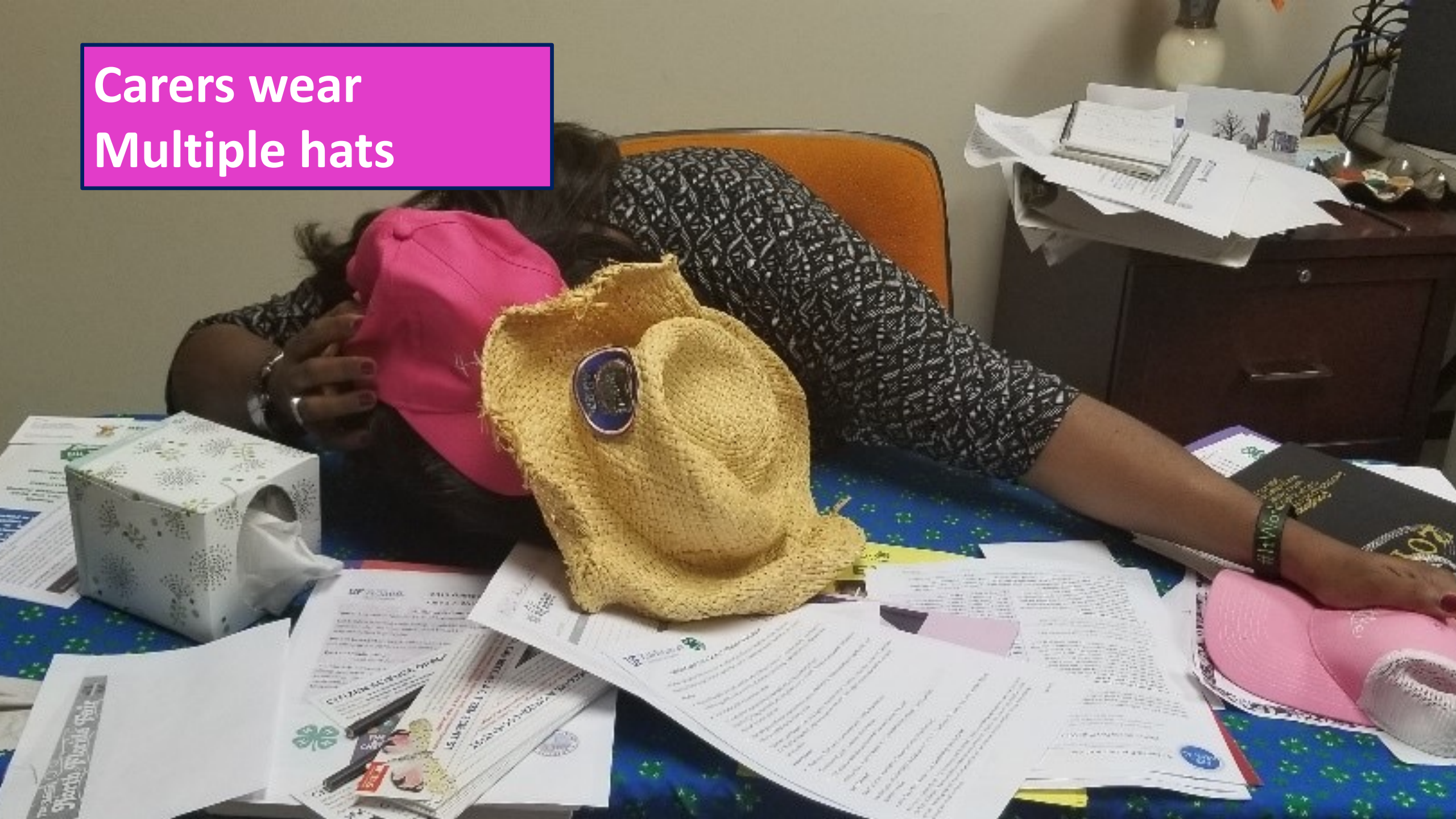
The care they give is unpaid.





[Reference; State of Caring in World](#)

**Carers wear
Multiple hats**



The Life of Carers: Physical impact

- The International Alliance of Carer Organizations (IACO) is a global network of carer organizations working together to increase awareness and recognition of carers.
- The IACO say whether through legislation, policies or programming, supports for the vital role of carers is **necessary for sustainable health and social care systems**.



The Life of Carers: Physical impact

- Although there are invaluable benefits to providing care, being an unpaid carer can be a long-term commitment and time-consuming, taking a heavy toll on the carer's health and well-being.
- Furthermore, when employed carers must juggle work responsibilities with their unpaid caring duties, there are potential negative economic impacts as carers withdraw from the workplace.



The Life of Carers: Physical impact

- **Caring is seen to influence emotional and mental health and is a predictor of poor mental wellbeing.**
- Half of all carers reported that their mental health has been affected by providing care for another person (Future Care Capital, 2019)



Social Impact of Caring: Social Isolation

- The causes of social isolation
 - 8 in 10 (83%) carers responding to Carers UK's State of Caring Survey 2014 have felt lonely or socially isolated because of their caring role. They told Carers UK that they feel lonely or isolated as a result of:
 - not being able to get out of the house much (55%, rising to 64% for those caring for 50 or more hours a week)
 - not being comfortable talking to friends about caring (36%)
 - not having time to participate in social activities (61%)
 - not being able to afford to participate in social activities (45%).

Social Impact of Caring: Social Isolation

I feel very much alone (Most carers)

I have little time for friends because of my role (Spousal Carer)

“I sometimes feel so worn out after sorting everything out for my son that I don't have the energy to have an outside interest.” (Parent Carer)

The biggest thing ...

“is not being able to afford or have the time to go out.

Also, the inability to relax and not worry about having to go home early because my husband needs me.

It's hard to enjoy social activities when you are tired and stressed and unable to 'switch off' from caring.

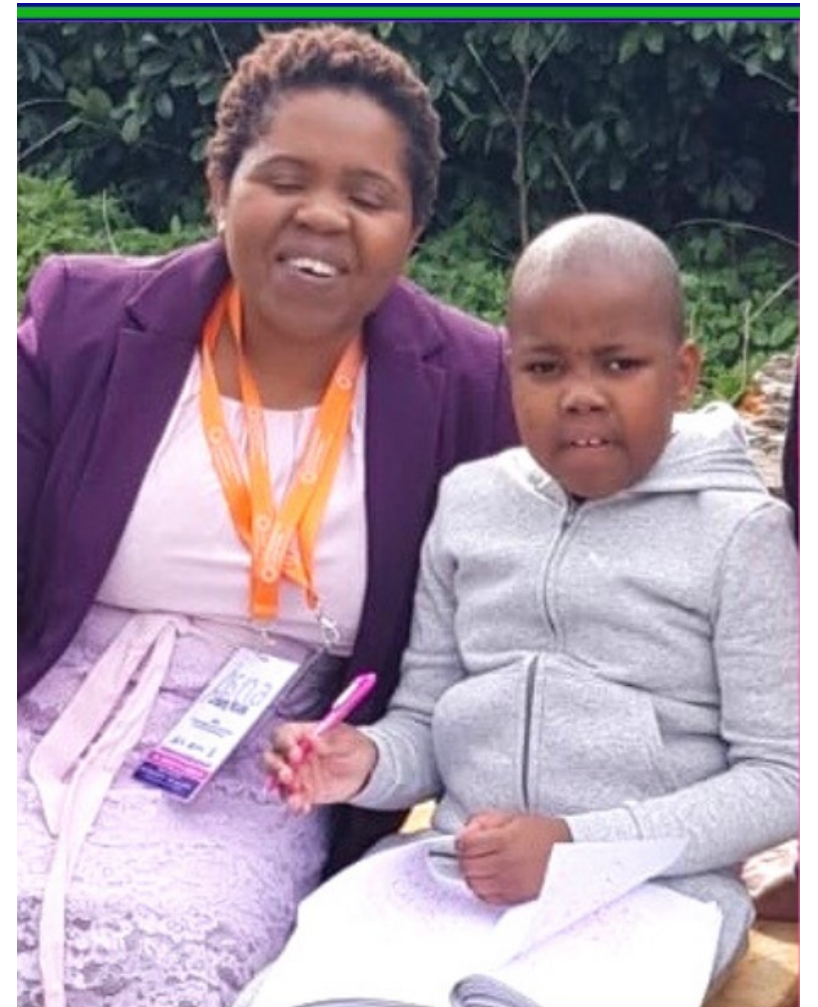
You miss activities and eventually people stop asking.” (Spousal Carer)

Social Impact of Caring: Social Isolation

- A study found that **emotional and mental health problems are more often associated with caregiving than physical health problems.** (CaresUK)
- Carers are more likely than non-carers to report high levels of psychological distress, which can include anxiety, depression, and loss of confidence and self-esteem.



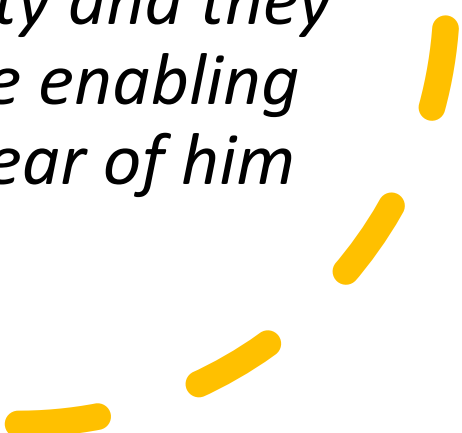
What are the experiences of Carers in the SDA church



A mini survey to determine church life and caring

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Experiences of support from the church community for carers

- *I believe I have found myself in a very fortunate position, where my church has a very strong disability team. The Disability Team Leader and team supported myself when I found myself in a crisis, they offered emotional spiritual support. The Leader has since played a very active part in supporting me at Review meetings to support my son. The church on the whole are very accepting of those with a disability and they welcome my son openly therefore enabling me to enjoy church without the fear of him being judged'.*
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Experiences of support from the church community for carer

As a global church I have not received any support or help. However on a local level my individual church has provided meals, regular calls would check on our welfare, visitation, flowers, cards and generally regular contact you see how doing and if they can help.

The church has not supported me as a carer. Only 2 individuals give me some support.

Before ASNA, I did not feel there was any support. I managed my child alone. ASNA raised awareness in my church and they also provide support. No church from the church.

Experiences of support from church community as a carer

As a carer, I cannot remember the church ever approaching me to establish whether I require any help or support. From what I understand, the women's ministry is responsible for providing support, yet I've never benefitted from any form of support.

The church has supported me by offering to take my son for days out, supported with his baptism, included him in the deacons team and always making sure he is not left behind. His vote is counted and he participates in communion and other church programmes obviously with support. The church is sensitive to the

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Experiences of support from church community as a carer

I feel invisible in the church. No one really carers or checks up on me. They check up on m mum but as a carer, no one seems to SEE me.

I feel Spiritually empty. I cannot go to church and when I am there, it is a prayer opportunity or pity party

Nobody seems to care really

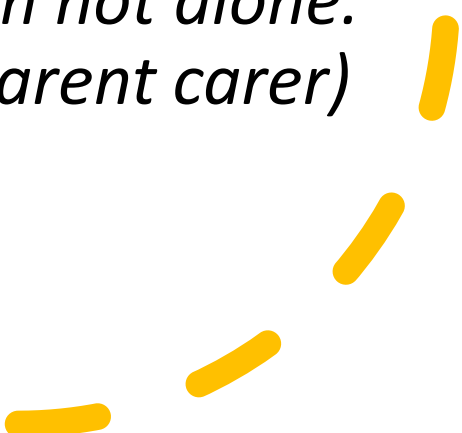
What are the experiences of Carers in the church community?

Carers in UK report personal experience of church life as a Carer

What is going well?

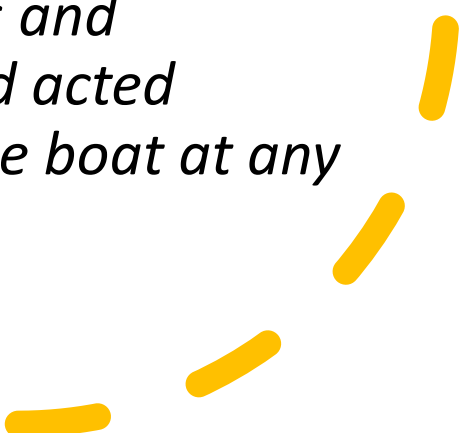
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What
support is
going well in
your church?

- *Nothing has gone well with the church in terms of support for myself and Ryan. Since I have been at home with him I have had no official visit from the leadership of the church. Only few people call and come to see us. (Parent carer)*
 - *Unable to respond to this question, because I did not know this support was available!(Spousal)*
 - *ASNA has helped me to know I am not alone. Peer support has really helped (Parent carer)*
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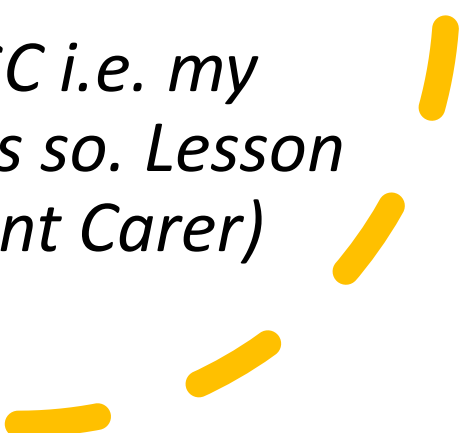


What is
support is
going well in
your church?

- *The church hold monthly disability sessions for all those with additional needs. These concentrate on the five senses, they involve fun activities such as art, praise and worship, plays, and are all very interactive.*
 - *Overlooking the disability and treating my son as an individual with capabilities that the Church could use*
 - *As parents we have been our children spoke persons and have worked hard with ASNA to spread awareness and that has changed the way the church looks at people with disabilities and fortunately the church has listened and acted because any of us could be on the same boat at any time*
- 

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What could
be
improved?

- *Nothing as in terms of the church I attend, however I am not sure everyone with a disability who attends other churches may get the wonderful experience from their church like I have. (Parent Carer)*
 - *I believe the conference needs to have a separate department that solely focuses on the needs of Carers in the Church. (Spouse carer)*
 - *Lesson study adjustments from GC i.e. my sons learns via pictures not words so. Lesson could be printed in pictures (Parent Carer)*
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What could be done better?

- *Things can only be done better if there was love in the church for each other. The leadership need to ensure that they are aware of the needs/situations of others.*
- *The church is operating in silos and if you're not in any of these groups then you don't matter. The silos need to be broken down. Members need to genuinely care for each other.*
- *Church could look into the emotional and mental health of its member especially carers as a matter of urgency. More proactive rather than reactive.*
- *Take time to check in on Carers.*

ASNA: Connecting Carers Network (Chairman ASNA) Nigel Nicholls



Apart from pastoral visits there is really no structure to support carers so the work that ASNA has been doing in this area is new and much needed.



ASNA helps to make connections and refer to the counselling service ASNA also gives time and space to listen and let people share at carers weekends.'



*Feedback from Carers at residential weekends have highlighted the need for this and the wilderness for carers to share their stories and help others. The real impact has been **carers helping carers** as they have direct experience.*

ASNA: Connecting Carers Network



Here 2 Hear – Monthly online peer and expertise support. Spiritual, social, mental and emotional support



Carers Breaks – Annual residential retreat in countryside for Carers for holistic support



Carers Creative – Creative workshops to support social and mental well being



121 Counselling support and sign posting to local Carers centres

What part can the church leadership and community play in addressing some of these challenges?

Experience of cares in UK churches

Recommendation to GC regarding Supporting Carers



Provide regular opportunities for raising the awareness of carers for church leadership at all levels (pre and post grad - training, internship, workers meetings)



Regular, consistent and sustainable support from all members and leadership at the local church level



Strategic mapping research to determine current support and to identify the gaps

How can we better support Carers in faith – based settings?

ASK

LISTEN

SUPPORT

REFLECT

CHECK IN



Yes, Carers Do Matter

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