

Autumn 2023

Newsletter

The Forces Additional Needs and Disability Forum



FANDF

Giving a voice to Forces families with additional needs and disabilities

Facilitated by

ssafa | the
Armed Forces
charity

ssafa.org.uk/fandf



Chair's welcome

As I sit on a chilly autumn evening and put pen to paper (or rather fingers to keyboard!), I can hear the sound of the wind blowing outside and the rain falling, and I am reminded that we are rapidly approaching winter. I cannot say it is my favourite time of year, but it does feel rather exciting to be looking forward to the joys of Christmas and the fresh start of a new year.

The FANDF committee have had two fantastic meetings since the biennial conference and are working hard to pull together plans for our two local events which will take place in 2024. Do keep an eye on your emails and our Facebook page to be updated when we release the details for these. It will be fantastic to see new faces at these events, and of course familiar faces too. As a committee, we love the opportunity to get out and meet FANDF members and share the lived experience and challenges which is so well known amongst many of us. Any feedback you pass to us about issues you are facing or concerns you have, will be shared to the relevant stakeholders where appropriate. If you wish to remain anonymous through this process, please just tell the committee member you are speaking to, and they will ensure this information is passed on confidentially for you.

In other news, in October we waved a very sad goodbye to Fran Robinson who has been with the SSAFA team for over 8 years and has been a fantastic Additional Needs and Disability Service Manager. The support she has given the FANDF committee and membership has been truly incredible, and we have been so fortunate to work alongside her. Fran will be very much missed at our committee meetings and FANDF events, but we are so excited to see where this next adventure takes her. Saying goodbye is something that we as military families are all too accustomed to, but it does give us a unique resilience and understanding that it is never really goodbye, but 'see you later' instead.

In September, SSAFA welcomed Sarena to the Additional Needs and Disability team as Service Support Officer, to cover Lucy whilst she is on maternity leave following the birth of her beautiful baby this summer. We are looking forward to working with Sarena as she supports the FANDF committee and are excited to introduce her to many of you at one of our events next year.

There is lots of talk within the military community about the New Accommodation Offer, which is planned to come into effect in Spring next year. I am sure there are many of you who are feeling positive about this change, but also lots of you who are feeling worried or uneasy about it. Please do look for support from the three families' federations, Naval Families Federations, Army Families Federation and RAF Families Federation with any questions or concerns you may have. As always, I encourage you to get in touch with the committee if you have any experiences you wish to share or any suggestions you would like us to take forward to the subject matter experts and MoD representatives, we have regular contact with. Please reach out via SSAFA's Additional Needs and Disability Advisor on anda@ssafa.org.uk.

Finally, I would like to wish you all a Merry Christmas and a very happy New Year. Maybe you will soon be indulging in eating far too much chocolate, drinking a little too much wine or seeing in the new year with a fresh outlook and plenty of New Year's resolutions. Wherever you may be and however you will celebrate the holidays, I hope it is a time that can be enjoyed with family or friends. I look forward to spending another year ensuring that our forces families with an additional need or disability have a voice that will be heard and will have the opportunity to see positive change in the areas WE need it most.

All the best

Stephanie Quintrell
FANDF Chair

Naval FF - <https://nff.org.uk/new-accommodation-offer-and-widening-accommodation-entitlement/>

Army FF - <https://aff.org.uk/advice/housing/new-accommodation-offer/>

RAF FF - <https://www.raf-ff.org.uk/housing3/new-accommodation-offer/>

FANDF committee invited to attend the Royal Centre for Defence Medicine summer festival

On 27 Jul 23, two of our board members, Noreen Hamnett and Emma Hughes had the opportunity to showcase the FANDF when they were invited to attend the Royal Centre for Defence Medicine (RCDM) Summer Festival at the Five Ways Old Edwardian Rugby Club in the Midlands.

The festival was a large-scale unit cohesion event which was organised to provide individuals from RCDM and their friends and family the opportunity to decompress. The event was about having fun. There was live music, kids' entertainment such as a bouncy castle and a petting zoo and a selection of culinary treats.

Noreen and Emma held a FANDF stall and were pleased to be able to engage with Serving Personnel and their families, spreading the word of the Forum and providing signposting to various organisations where needed.

It was a great opportunity to engage with the unit as a whole but also to chat with those who have family members with an additional need or disability.

The committee work tirelessly to get the FANDF name out there, if you are aware of any unit events where you would like to see the committee in attendance, please do reach out to us.



Just one thing

During our Autumn event last year, we asked our families to provide details of “Just one thing” that they had found useful that they would recommend to others. These recommendations could be anything from a TV series to a film or book.

We received so many recommendations which we would love to share, please see below for some of those recommendations:

Float – A Disney Pixar short film

The Good Doctor – TV Series

Autism explained to children – YouTube

Pablo – CBeebies

Nessy – a Dyslexia App

The A Word – TV Series, iPlayer

The reason I jump – book by Naoki Higashida

The out of sync child – Book by Carol Stock

The whole brainchild – book by Daniel J. Siegal and Tina Payne Bryson

For the love of Anne – book by James Copeland

My brother is an astronaut – by Michael Rundle

The curious incident of the dog in the night-time
– Book by Mark Haddon

Wonder – Book by R.J Palacio and also adopted in film on Netflix

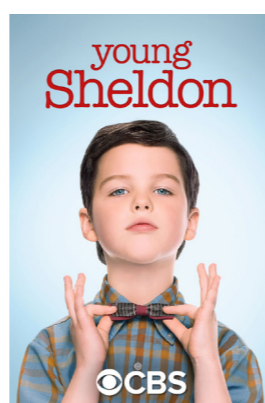
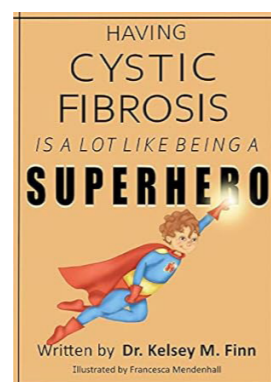
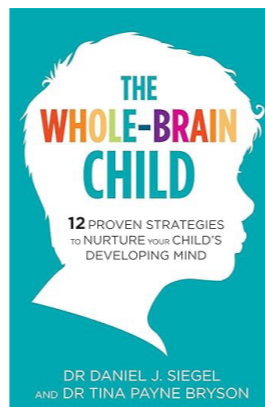
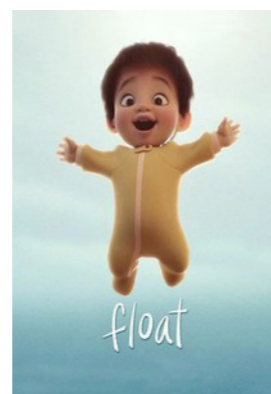
The girl with the curly hair – Book by Alis Rowe

The life you never expected, thriving while parenting special needs children – book by Andrew and Rachel Wilson

Young Sheldon – TV Series

Having Cystic Fibrosis is a lot like being a Superhero – Book by Kelsey M Finn

if you have any recommendations you wish to share, please contact CS.ANDA@ssafa.org.uk with the details and we will be sure to add them to the next newsletter.



NEW DIAGNOSIS - WELCOME TO HOLLAND - by Emma Hughes - Committee Member

In 2015, my second son Chester was born and having suffered complications was later diagnosed with Cystic Fibrosis, a genetic life limiting condition which affects the lungs and digestive system. I was completely blindsided and was left devastated and heartbroken.

In the very early days post diagnosis I simply couldn't function, I was in complete denial, and I found the only way I could function was to take one day at a time, too scared to look to the future, because at the time, the future seemed uncertain.

I struggled to come to terms with his diagnosis and what it meant, I was completely unaware of a family history of Cystic Fibrosis and having had a relatively easy first pregnancy resulting in a healthy baby, I never even considered the possibility that my second pregnancy and child would be any different.

Chester was admitted to Birmingham Children's Hospital for surgery when he was just a few days old, he suffered from a blocked bowel which was an initial indicator that Chester might have Cystic Fibrosis. I remember going completely against the doctor's orders and googling the condition, googling symptoms, and even trying to find out the statistics for statistics, praying we would receive good news.

Waiting for the results of the genetic testing felt like a lifetime, I found myself hounding the Doctors every morning on the ward round for the results. It was pure torture.

After a very long painful wait, I was informed by Chester's nurse that the results were back and that I needed to call my husband in, he had literally just left the hospital to take my other son Oakley swimming. I knew there and then that it wasn't going to be good news.

We were led as a family, into the staff rest room which smelt of microwaved noodles, where I saw four people sat straight faced. I immediately tried to walk out, not wanting to hear what was so obviously painted on their faces but was led in by my husband where we sat down.

My world came crashing down as they told us that Cystic Fibrosis had been confirmed, my heart broke and couldn't control the tears that fell, Oakley, completely unsure of what was going on held my hand and asked me what was wrong. I couldn't speak, I felt sick and completely numb. Realising that it was distressing for him, Oakley was led out to the playroom by one of the nurses, after which the Doctor's talked to us about treatments amongst other formalities, if I am honest, I don't remember anything about that conversation, even now it's a complete blur.

In the days and weeks that followed I felt broken, constantly asking why him, why us, I went through various stages, from complete denial to anger. No parent plans for this, and I certainly hadn't.

After reaching out to a CF parents Facebook page, I was overwhelmed by support from other newly diagnosed parents, without which I don't think I would have coped. I recall talking to another Mum who shared a poem with me called “Welcome to Holland”. What a game changer this was for me, it made me look from a different perspective and whilst I don't think I will ever come to terms with Chester's diagnosis, at the time it really helped me to learn to see past it. No, we hadn't planned on Cystic Fibrosis being a part of our lives, but here we were on this different path, and maybe it wouldn't be so bad, just different from what we had initially planned.

I am now 8 years on from Chester's diagnosis and whilst the darkness of his diagnosis never leaves, I have learned that it does get a little easier with time.

I am quite vocal about being the parent of a child with a complex medical condition and I often have newly diagnosed parents reach out to me, one thing I always share is share Emily Kingsley's “Welcome to Holland” in the hope it gives them the same comfort it gave me and as a reminder that despite the destination not being the one that was expected, it doesn't mean that it won't be just as perfect.

Welcome to Holland

by Emily Perl Kingsley

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books 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.

NUMBER 10 VISIT - Noreen Hamnett and Michael Mayes

On 21 June 2023, two members of the FANDF committee were invited to go to 10 Downing Street as part of a delegation from SSAFA as part of an Armed Forces Reception. The two members selected to attend from those that had expressed their availability (by the trusty names in a hat method) were Noreen Hamnett and Mick Mayes. Both were delighted to have been selected.



The event was to be hosted by Akshata Murty, the wife of the Prime Minister, and Johnny Mercer, Minister for Veterans' Affairs.

The SSAFA delegation was made up from several different people that have been supported in some way by SSAFA, or those that offer the support. As well as FANDF there were people that had been supported through the adoption process, a veteran who had been blinded, a 94 year old RAF veteran, a service widow volunteers from SSAFA Central London Committee and more.

Once through security we were led through the house, to the garden which was covered in beautiful sunshine. We were treated to a finger buffet and cake. As it was Noreen's birthday extra cake was allowed!

Akshata Murty and Johnny Mercer both gave speeches recognising the role military families play, the sacrifices made and reaffirming commitments to veterans.

We had a brief chat with Johnny Mercer, but then spent about 10 minutes on our own speaking with Akshata Murty. We highlighted the role of FANDF supporting the people we do, and some of the challenges faced by service personnel and their families that have members with additional needs or other disabilities. She was very interested in what we had to say and asked a number of questions finishing up by thanking everyone for the support they give.



All in all it was a very enjoyable couple of hours, which we both left thinking that we had been listened to and to top it off, Larry the Downing Street cat made an appearance as we were leaving.

Brave Parents Charity

Brave Parents is a registered charity created to provide self-care opportunities to parents who have children with complex medical needs*.

We recognise that many of these parents forget to care for themselves. They work so hard to keep their child well that their own needs always come second.

However, over time this can have an impact on the mental health of the caregivers and whole family unit.

We create opportunities for Parent Carers to have some well needed 'you' time to support their mental health and well-being.

From pamper '... for you' and Hospital Boxes to in person events and local meets, we hope to encourage self-care and highlight that it is essential, especially through hard times.

Follow our social media pages or [sign up to our mailing list to find out more.](#)

Instagram @braveparents
Facebook @braveparents1

*'Complex medical needs' refers to children who have been diagnosed by a medical professional, with an illness, disability or sensory impairment (sight and/or hearing impairment) that requires substantial daily support from a Parent Carer.

Brave Parents - Registered Charity No. 1204544

Please note, this charity is not affiliated to SSAFA and is being provided for your information, as with any posts detailing other charities, we recommend that individuals conduct their own research in the first instance.

Sailability

Whitefriars Sailing Club (WSC) is a members-only sailing club based at Lake 26 (85 acres of water) in the Cotswold Water Park near Cirencester, run by volunteer members. WSC is a RYA Recognised Training Centre (RTC) for sailing and powerboat instruction, offering RYA sailing and powerboat courses to members of the Club and other local groups.

Sailability at Whitefriars (S@W) is a registered charity, that seeks to provide sailing opportunities to those individuals and groups with disabilities from the local community, from sailing experiences through to sailing instruction, depending on individual circumstances. S@W works in close collaboration with WSC RTC at Lake 26 and is run by volunteers who are trained in all aspects of this sailing provision and is, in the majority, funded by charitable donations and session fees from the participants. S@W sessions are currently run on Wednesdays and Thursdays, April to October. A combination of adapted and standard dinghies are used whilst sailing. Volunteers additionally man safety-bats whilst participants are on-water. All S@W volunteers working with vulnerable children and adults are DBS-checked.



Registered charity: 1187670

Building for the future

As history has shown us, S@W year on year has developed its resources in terms of volunteers, boats, and facility improvements. This year has been no exception, and plans are already underway for the future.

Our latest addition was launched this season, another RS Venture Connect sailboat, bought because of its versatility to meet the many different and challenging needs of our clients. It has now been named the "Wooden Spoon" as gratitude for the huge contribution received from the charity of that name.



In conjunction with Whitefriars Sailing Club we are always looking at how the facilities can be improved, currently the jetty is being reconstructed following deterioration of the structure. For years we have been battling with a padlock on the gate, but coming soon there will be an easy access barrier in place. Looking further into the future, there are plans for a much-needed recreation area where individuals and groups can sit, have lunch, or just relax away from the busy hubbub of clubhouse activities during the sailing sessions. **Watch this space!**

As ever, we are grateful to all our funding partners, this year they are: Wiltshire Area Board Malmesbury and Bernard Sunley Trust – grants towards the Quayside Improvements; Mid-Counties Co-operative – grant towards the purchase of Picnic benches; Gloucestershire Masonic Charity Action – grant towards the proposed picnic shelter; The Wooden Spoon – funding towards signage for the new RS Venture.

The Fund-Raising Team works hard to ensure the future financial stability of the charity and values its relationship with all funders and donors to promote awareness of disability and meet the needs of disabled people.

Volunteer spotlight: Louise (Trustee and Bookings Manager)

I first came to Sailability in 2014 as a Sailor, and soon became involved in Volunteering too. I am registered Blind and used to be a Teacher of the Deaf. As my sight deteriorated I had to give up teaching as I was no longer able to see my students signing to me, read what they had written, and towards the end of my days in the classroom I kept walking into things and tripping over. I am also Mum to two neurodivergent young people. Rather than let my vast experience of working with people with Special Educational Needs and Disabilities go to waste I have channelled my energies and expertise into supporting our sailors.

I am often one of the first people to welcome our new sailors, having a friendly chat on the phone before their first visit to discover their needs and explain what we do. I offer a Guided Tour when they arrive and introduce them to some of our fantastic Volunteers. I love meeting and greeting our Sailors and their carers and families in the Car Park with clipboard and walkie talkie in hand.

When I get the opportunity to sail my own HANSA 303 called Hakuna Matata (meaning No Worries in Swahili), I usually try to get round the lake to say "hello" to everyone. Volunteering is now at the centre of my life and is my raison d'être. I also Volunteer with the local Guide Dogs Fundraising Group alongside my German Shepherd/Golden Retriever Guide Dog Axel, and as a Sensing Nature Guide at Westonbirt Arboretum. Working alongside other Volunteers is amazing as everyone is there because they want to be there. At Sailability@Whitefriars we have a fabulous team atmosphere and I gain so much from being a part of something this special.



New volunteers are always welcome - contact: sailability@whitefriarssc.org

2023 REVIEW

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