

Involvement in church services

Inclusive churches are places where people don't have to appear healthy to attend. They allow honesty and have a culture of acceptable vulnerability.

Some possibilities:

- Provide comfy seats/somewhere to lie down or provide a separate room with a video link monitor, comfortable temperature and furniture, sound reduced, lights low, minimum stimulation. This would mean I could still fellowship on my low days without the cost to my health being too great.
- Accept and prepare for last minute cancellations due to illness.
- Plan an occasional quiet service.
- Give plenty of advance notice of what's planned for church activities.
- Communicate that it is ok to attend part of a service.
- Consider skypeing to a life group or broadcasting live on closed Facebook group for a service.
- Daytime afternoon activities can be more accessible.
- Keep asking even when I don't come... it is important to be included in the invitation.
- Pre-record my testimony or a word I want to share, as that can be easier than sharing in the service, or split my sharing/word into two parts.
- Set up prayer partners and prayer chains which include me.

- Occasionally run a very small group at my home if I am up to it.
- There might be IT or social networking or admin I can help with if I am housebound with a laptop for long periods of time... do ask!

Thank you!

Thank you so much for taking the time to read my message.

Any questions? Please ask me. The easiest way for me to receive contact is by:

- Text message
- Email
- Phone
- In person

My contact details

Shona Smith prepared this leaflet and advocates for people with chronic illness. To enquire about possible opportunities for training/awareness raising for churches and church leaders, you can reach her at shonakatesmith@gmail.com

I have a chronic illness

I have a chronic illness. It makes regular attendance at a church service challenging but I still very much want to be part of the body of Christ... in fact, I need my brothers and sisters in Christ like never before!

I have:

- M.E. (Myalgic Encephalitis) also referred to as Chronic Fatigue Syndrome
- Fibromyalgia
- Other

There can be a lot of misunderstanding, unrealistic expectation and sometimes hurt caused when friends and family don't understand the limitations and daily challenges of my condition. If you want to understand me better you could:

- watch the documentary UNREST on Netflix
- read about "spoonies" <https://butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory/>



- check out this awareness raising campaign: <https://millionsmissing.meaction.net/>



- read this information page www.fmuksupport.org/what-is-fibromyalgia/



Please understand...

Church services and most social gatherings are challenging for me. Here are some ideas which would help to include me on the days when I am feeling strong enough to attend. Please understand that...

- Church is utterly exhausting cognitively and physically, so it's a huge ask to expect very sick people to go.
- Sometimes the battle has been fought to merely attend church and there is nothing left for socialising.**
- I feel more vulnerable at some times than at others and can maybe attend a service but not interact... it's not unfriendly, it's just my reality.
- There are even challenges in being upright...sometimes I need to lie down! But this isn't possible without comfortable seating.
- I only have a fraction of a healthy person's energy each day - everything I do requires a portion of that energy.
- Socialising and being with more than one or two people are very high energy activities for me.** (Meeting for a coffee is down time for a healthy person but is a serious commitment of energy for someone like me.)
- Noise and bright lights are draining or even painful, lots of stimuli from different directions also drains.
- I often have to choose between the social aspects of church, participation in worship and concentrating to listen to preaching.
- An outing of any sort requires energy and planning. It is rare that I can do activities on consecutive days and often have to budget extra, quiet, horizontal rest time for several hours either side of an outing, including church.
- Post-Exertional Malaise (PEM) - the increased symptoms of illness - can last 2-3 days after increased activity and can leave me ill for a week or more or even trigger a "crash" and leave me bedridden.

Things I'd like you to know but are difficult to say....

- Remember I am a person before my illness.** Don't let it define me!
- I want to be well more than anything! I hate missing out! I desperately want to be healthy enough to throw myself into church services and social occasions. I'd love to:**

(for personal completion)

Unseen aspects

- I only make it to church on good days** and even then I pay for the extra energy it has cost me for days or even weeks after. Relentless daily struggles include apportioning energy for showering, cooking, cleaning, talking, reading, even watching TV. Once energy is gone, I have to rest and wait for more.
- Often my skin is so sensitive I can't bear anything to touch me, even clothes hurt... so please ask before offering me a comforting hug as you may cause me pain!
- Sometimes the waiting gets too much and I am really discouraged, despondent, depressed... I do have peaceful trusting seasons too. I might need to grieve for the life I have lost.
- There are extra challenges to being alone or living alone with chronic illness. When I am very ill, "crashing," I really need practical support.

Ideas for support

- Regular contact with church leaders and members** are lifelines! Texts, emails, social media, letter, church notice sheet, short phone calls...
- A named contact** in church for me to text/ring when things are so extreme I haven't shopped/have no food/need to see another non-judgmental face?

- Mutual communication please**, not all initiated by me, the chronically ill person, and not one off. **The single biggest problem with being too ill to regularly attend church is that I am isolated, lonely and feel forgotten and passed by... regular contact will help me feel included and valued.**
- Visits** - with or without conversation (on bad days speech isn't possible).
- Prayer** - For right now and for long term hopes. **I welcome prayer but appreciate people asking permission and even what I want prayer for (it's not always about the illness!).** The hope is that I will be totally healed but it is rare that happens immediately, so please don't make me feel responsible for delayed answers to prayer. It is inappropriate to blame me for my sickness and is an abuse of power to suggest to a vulnerable person that they are responsible for their condition.
- Practical support** is always appreciated! Suggestions... occasional meals, light housework, laundry, lifts, supporting family with lifts to include children in activities, spending time with me to release my regular carer to have opportunities to do things for themselves, checking up on how my main carer is coping. **The full burden of house and family falls on my carer in very ill periods and it can be suffocating, so try to be aware of these and other changes when extra practical support would be so helpful.**
- Often small groups/home groups are better for offering ongoing support...** maybe because the work is shared.
- If you want to initiate help**, please be led by me as the chronically ill person - ask me to be specific. If you've supported me for a while consider building in regular reviews - am I still coping, would I like anything different in support.