



FND
WHAT NOW

SUPPORT GROUP HANDBOOK

FND - What Now? is a patient-led and registered non-profit company (NPC) in South Africa (SA). We provide support to people diagnosed with Functional Neurological Disorder (FND), and those who fulfill the roles as carers.

The focus of this handbook is to provide clear guidelines on how our support groups are structured, operates and the responsibilities maintained by both our organisation and each member.

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WELCOME MESSAGE



Audrey Bart

Founder and Support Group Leader

Functional Neurological Disorder is a debilitating neurological condition that significantly impacts daily functioning, presenting with a myriad of physical symptoms without a known medical cause. It affects people from all walks of life and across all age groups. If you're reading this and you are diagnosed with FND, or know of someone who has FND - You are not alone anymore.

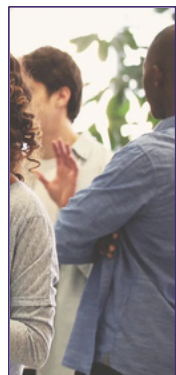
A warm welcome to our support group. As one of our newest members, we hope you'll find comfort, support, and healing in our meetings. Feel free to share at a pace that's most comfortable for you - we value your participation.

Our group is built on understanding, respect, and shared experiences. Together, we create a safe space where questions are welcomed, emotions are honored, and every step forward is celebrated, no matter how small. Remember, your journey is unique, and we're here to walk alongside you.

You've already shown tremendous courage by taking this step. We look forward to getting to know you and being part of your support network.

With warmth and understanding,

Audrey





OUR COMPANY

FND - What Now? is a registered non-profit and patient-led company (NPC) in South Africa (SA). We are dedicated to addressing Functional Neurological Disorder (FND), a debilitating neurological condition. FND significantly impacts daily functioning, and presents with a myriad of physical symptoms. There is no known medical cause to date. Our focus is to raise awareness and debunk myths about FND, and support each person on their healing journey. Furthermore, we support research to better understand this complex disorder.

Our Mission

Our mission is to deliver vital public benefits and social services to individuals with Functional Neurological Disorder (FND) and related conditions in South Africa (SA). We strive to create meaningful social impact by:

- Empowering patients on their healing journey, regardless of their socioeconomic background.
- Connecting individuals to trusted healthcare professionals to enhance their care experience.
- Reducing stigma associated with FND through education and advocacy.

By providing these essential public services, we aim to improve the lives of those affected by FND and foster a more understanding and supportive society.

Our Vision

Our vision is to improve the quality of life of people in both urban and rural areas across South Africa (SA) who suffer from FND and FND related symptoms.

THE ROLE OF A SUPPORT GROUP

Support Groups serve as a safe and supportive community where people with first-hand lived experiences can connect and support one another without fear of judgement. They provide an invaluable platform for individuals facing challenging experiences and chronic health conditions like Functional Neurological Disorder (FND) and other mental health conditions. Through shared experiences, these groups create a space where members feel understood, respected, and believed.

Benefits of a Support Group:

- Access to educational resources and professional referrals that facilitate healing and provide stability.
- A confidential environment for sharing difficult experiences and emotions.
- Opportunities for personal growth, resilience building, and skills development.
- Meaningful connections that help reduce feelings of anxiety, loneliness, and isolation.
- Participation in research studies that advance understanding of conditions like FND.

The Power of Group Dynamics:

Support Groups thrive on collective strength, which is essential for both group longevity and building resilient communities. This manifests through:

- Advocacy for improved healthcare policies and resource access.
- Development of leadership skills among members.
- Recognition and utilisation of members' diverse talents and experiences.
- Peer-to-peer support and knowledge sharing.
- Building awareness and understanding in the broader community.

Important Note: While support groups offer valuable peer support, they complement but do not replace professional medical treatment, therapy, or other healthcare interventions. Members are encouraged to maintain their existing medical care while participating in the group.

OUR FND SUPPORT GROUP

The need for a support group became evident as Audrey Bart searched for resources during her own healing journey with Functional Neurological Disorder (FND). Drawing from her medical background as a medical technologist and her love of learning, Audrey gained a wealth of knowledge and insights through extensive research of books, papers, and other FND and mental health resources. This led her to establish FND - What Now? support group, which launched in November 2022, with the assistance of The South African Depression and Anxiety Group (SADAG).

SADAG, established in 1994, is a non-profit organisation and registered Section 21 Company. Their board includes psychiatrists, psychologists, general practitioners, and patients. The organisation serves as an advocacy and support group network for thousands of South Africans living with Mental Health Issues. SADAG's mission is to eliminate discrimination and stigma in Mental Health while supporting, educating, and assisting the public, patients, and their families regarding available resources and treatment options that lead to recovery. They coordinate a network of over 170 Support Groups throughout South Africa (SA).

The FND - What Now? support group was therefore created to provide aftercare and bridge the vital gap between professional medical treatment and therapy, and the ongoing need for supplementary support in South Africa (SA).





FND
WHAT NOW

Registration No: 2024/319828/08

FREE FND ONLINE SUPPORT GROUP

Call Us
Living
with FND?
You're
not alone.

OUR PROCESS

- ✓ Adults, aged 18yrs+
- ✓ Google Meet video call screen for all new members
- ✓ Complete a membership intake form
- ✓ Receive our link upon confirmation
- ✓ Tuesdays, weekly @ 7pm SAST

Join our supportive community where we come together to understand, share, and grow.

Unique theme-based meetings offer a fresh perspective on living with FND.

We support each other through reflection and discovery, as we experience our individual healing journeys.

We operate under the **SADAG** flagship.



@fndwhatnow



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HOW WE OPERATE

As part of our partnership with SADAG, we offer free online support group sessions. These meetings are held live (synchronously) at regularly scheduled times, allowing members to connect and interact in real-time.

How We Operate:

- Our meetings take place Tuesdays, weekly, at 7pm - 8pm South African Standard Time.
- We use the Google Meet and Microsoft (MS) Teams platforms.
- You will receive a new link every week to ensure privacy and security. Do not share it publicly.
- For added privacy, we do not record any of our support group meetings.
- All meetings are conducted in English.
- If you have an emergency outside of our group times, please reach out to Audrey privately. Cell: +27 (0)76 291 3442 OR Email: fndwhatnow@gmail.com. We will respond within a 24hr period.
- Free counselling services are available 24/7 from The South African Depression and Anxiety Group (SADAG). The contact details are listed below on Page 8.

How We Present:

- Our content is carefully curated to support optimal healing outcomes.
- Our meetings are theme-based, which allow us to understand all the different aspects and complexities of FND.
- We incorporate presentations, interactive and creative exercises, guest speakers and venting sessions.
- We support each other emotionally through active listening and snapping our fingers in solidarity during our venting sessions.
- We encourage members to ask clarifying questions as they reflect on the progress of each person's healing process.
- We share different resources that supplement our understanding of FND, and other FND related subjects.
- Members are encouraged to communicate their needs by specifying what kind of support they're seeking from the group.

Our Leadership:

Support group leaders for our FND groups are trained volunteers. They facilitate meetings where people affected by this condition can connect and find mutual support. Drawing from personal experience with FND (patient-led) or specialised training, they create safe spaces for members to share their unique symptoms, challenges and victories.

Support group leaders utilise a wide range of information and resources from different research papers, books, online content and other healthcare sources and platforms, to help members navigate their FND journey and find strength in community.

HOW DO WE OPERATE

Our Engagement Guidelines:

- We maintain a strict code of confidentiality within the group, and each member's privacy and dignity is respected. What's shared in the group, stays there.
- Members are encouraged to participate and share respectfully, mindfully, equally, and at a pace that's most comfortable for each person.
- We avoid using any vulgar, condescending, or discouraging language, tone or behaviour.
- Your well-being and that of the other members are very important to us. Members must be sober during our meetings. Please do not attend if you are under the influence of medication, alcohol or substances that affects your awareness.

WhatsApp Group Chat:

- Additionally, we have a group chat option available where members are encouraged to share resources and support to one another.
- It is completely optional to join our WhatsApp group chat.
- It operates from Mondays to Saturdays, 08:00am - 5:00pm
- All members are asked for consent to join at our Tuesday meetings. Alternatively, we will request consent via email.
- New members are asked to introduce themselves when they join the group chat.
- You can familiarise yourself with our group chat rules listed in the description section.
- Members are encouraged to connect privately and to form friendships outside of the group chat. We do so with the utmost respect of each person's personal boundaries, and in alignment with the views of our organisation, FND - What Now Non-profit Company.
- To manage notifications, you can mute the chat or customise alert settings in WhatsApp.

Supporting You Through Difficult Times:

We understand that living with FND can sometimes feel overwhelming, and you may experience dark thoughts or feelings of hopelessness. Your well-being matters deeply to us, and while our support group provides a caring community, there are times when professional support is essential for your safety.

If you're having thoughts about harming yourself, please know that you're not alone, and caring professionals are here to listen without judgment, day or night:

- SADAG Caring Support Line: 0800 567 567 (available 24/7)
- WhatsApp Support Line: 076 882 2775 (available 24/7)
- Emergency Care: 10177 (from landline) or 112 (from cell phone)

HOW DO WE OPERATE

Supporting You Through Difficult Times:

We encourage you to:

- Reach out to these dedicated support services.
- Connect with your healthcare provider.
- Visit your nearest emergency center.
- Share your feelings with someone you trust.

Your journey and your life are precious. While our group provides peer support, we'll always guide you toward professional help during times of crisis. Remember, reaching out is a sign of strength, not weakness.



Becoming a Support Group Leader:

Our support group operates under the flagship of The South African Depression and Anxiety Group (SADAG). SADAG offers a free Mental Health Support Group Leader training for anyone interested in starting a support group in their community. Click "Support Groups" on their website: www.sadag.org to learn more.

MEMBER PARTICIPATION

Being part of our FND support group means joining a community where your experience matters. Each member plays a vital role in creating a safe, understanding space - whether through sharing your own story, offering gentle support to others, or simply being present. Living with FND brings unique challenges, and your participation helps build a network of understanding and hope. Some days you might feel ready to share, while other times you may prefer to listen and reflect. Both are equally valuable. Your insights, questions, and journey contribute to our collective strength, helping to break down isolation and build connections. Together, we create a community where everyone's path with FND is acknowledged, respected, and supported.

What You Need To Know:

- You must be 18 years of age and older to join.
- You must reside in South Africa (SA).
- You must be diagnosed with FND, and that the diagnosis was received from a registered and qualified neurologist.
- We screen each potential member via a Google Meet video call, followed by completing our membership intake form. This is a time for us to get to know you and assess your symptom needs.
- You will be required to complete our intake form for our administrative purposes.

Please Note: Your personal information and privacy matter to us. We do not share your information with any third-parties without your written consent.

How We Conduct Our Meetings:

- We host free weekly online meetings, every Tuesday, at 7pm - 8pm SAST.
- Our meetings are hosted using the Google Meet and MS Teams platforms.
- You will receive a new link every week to ensure privacy and security.
- All meetings are conducted in English.
- Our content is thoughtfully selected to promote effective healing and recovery.

Time Management:

To help make our sessions comfortable and supportive for everyone, we've set up some gentle timing guidelines. These apply to all members.

- We'll start at 7pm and keep the first 5 minutes open for everyone to join in.
- If you know ahead of time you can't make it, just drop a message by 6:30pm on our WhatsApp group chat or privately to the number 076 291 3442.
- Not feeling well? Your health comes first – please rest and take care of yourself.
- To keep our discussions flowing smoothly, we kindly ask that you do not join after 7:15pm.

MEMBER PARTICIPATION

Meeting Access Instructions:

- You will receive a meeting link via email.
- Click the link a few minutes before the scheduled time.
- Ensure your microphone and camera are working.
- Minimise background noise by using earphones/headphones.
- Sit in a comfortable and calm space.
- For the MS Teams connection - use the app or web browser to log in.
- Use the "raise hand" feature to indicate when you wish to speak.

Growth and Advancement Opportunities:

As members progress in their healing journey, we encourage growth beyond regular group participation. We offer voluntary roles (either as a volunteer or elected Board member) within our organisation based on:

- Individual healing progress
- Personal readiness
- Skills and interests
- Available time and energy
- Physical capabilities
- Access to a computer or laptop
- Stable internet connection

Note: While support group membership isn't intended to be lifelong, we accommodate longer-term participation based on individual needs and organisational capacity.

Healthcare Referral List:

We are compiling a resource list of healthcare practitioners who support people with FND. If you know of such practitioners and would like to share that with us, you can contact Audrey directly. All candidates are closely vetted before we include and share their services.

You matter to us! We want you to know that we support you wholeheartedly through your healing journey, whatever that may look like. Each person has a different story to tell.

MEMBER PARTICIPATION

Friendships Beyond The Support Group:

We love seeing supportive friendships develop between members! While we encourage these connections, here's what you should know.

When connecting outside our official support platforms:

- Meet and interact with mutual respect, understanding and at your own comfort level.
- Trust your instincts and maintain personal boundaries.
- Remember that these friendships are your personal choice.

As a support organisation, we:

- Can't oversee private friendships or resolve personal conflicts.
- Don't manage private interactions between members.
- Won't be involved in any personal arrangements or agreements.

Keep it friendly, keep it respectful, and stay safe! If you ever feel unsafe or experience harassment, please contact the appropriate authorities.

Leaving The Support Group:

We understand that circumstances change and members may need to leave the group. If you wish to leave:

- Notify the group leader via email or private message.
- Contact Audrey Bart.
- Cell: +27 (0)76 291 3442
- Email: fndwhatnow@gmail.com
- Complete a brief exit survey (optional but appreciated).
- Remove yourself from the WhatsApp group.
- Your information will be kept confidential per our privacy policy.
- You are welcome to rejoin in the future through the standard intake process.

IN CLOSING

As we close this booklet, remember that your presence in our FND support group matters. Each step on your healing journey, no matter how small, is significant. While living with FND brings unique challenges, you don't have to face them alone. Together, we create a circle of understanding, hope, and mutual support. Whether you're just beginning to understand FND or have been living with it for years, this group is here to walk alongside you. We look forward to sharing this journey with you, celebrating your progress, and supporting you through challenges. Remember, healing happens at your own pace, and in this space, your experience is valued, your voice is heard, and your journey is respected.

With warmth and understanding,
The FND - What Now? Team



INSPIRING QUOTES

"Sometimes the strength within you is not a big fiery flame for all to see, it's just a tiny spark that whispers softly 'you got this, keep going.'" - Unknown

"Vulnerability sounds like truth and feels like courage." - Brené Brown



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Cape Town, South Africa

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Transformation
through
Understanding

Registration No: 2024/319828/08