Light the Fire

Building a Cardiac Arrest Survivorship Community

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suddencardiacarrestuk.org

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Dedication

For everyone who has ever felt alone after a cardiac arrest—survivors and co-survivors alike—and for those working to ensure that no one has to feel that way again.

> *"I was pretty desperate, a 'sadness' had hit, after an initial euphoric 'I beat death' attitude. I was sat, on my own, late at night, feeling like I'd never stop crying again. I was searching online for anything to help me make sense of how I was feeling—why couldn't I feel happy, why wasn't I grateful to be alive? I stumbled across this group, and joining was THE best thing I did after my cardiac arrest. People understood, they just 'got it', the support was incredible, I wasn't alone. My 'new normal' was normal, in my completely upturned, abnormal world. This group saved my sanity."*
>
> *— Charlie D*

More voices from our community appear at the end of this guide.

Praise for Light the Fire

> *"This is truly a fantastic text! It is well written, personal, and beautifully structured. Having been part of starting a peer support network ourselves, we recognise so much of what you describe. We would really have benefited from this guide early in the process, but even now, six years later, we realise how much we still have to learn. Anyone considering starting a peer support network would benefit from having access to this book."*
>
> *— Stefan Jutterdal and Johan Israelsson, co-founders of the Swedish cardiac arrest survivorship network*

Foreword

In 2026, NHS England considers out-of-hospital cardiac arrest "an orphan condition". Meaning a condition that naturally does not belong to any medical speciality. Sadly, what this means in the real world is that no one speciality stands up to "own the patient" and drive care and quality improvement. I believe in 2026 what I believed in 2014, that Cardiology must be at the centre of cardiac arrest care, but we need multi-disciplinary support from many allied skillsets to truly deliver what the patient needs.

As a cardiologist, I spend my days treating the physical aftermath of cardiac arrest—the blocked arteries, the damaged heart muscle, the complex decisions about devices and medications. This work is essential. But over years of practice, I came to understand that survival is only the beginning of a much longer journey. The patients who left my care with functioning hearts often returned with questions I was not trained to answer. *Why do I feel so different? Why does my family not understand? Why am I grieving a life that technically continues?*

In 2014, I established the UK's first dedicated Care After REsuscitation clinic at the Essex Cardiothoracic Centre, bringing together cardiologists, neuropsychologists, rehabilitation and specialist nurses to address these very questions. What that work taught me is clinical expertise, while necessary, is not sufficient. Survivors need something medicine cannot prescribe—connection with others who truly understand.

This is what Sudden Cardiac Arrest UK provides.

I have watched this organisation grow from Paul's initial pub meet-up into what is now the world's largest national cardiac arrest survivorship community. I have seen the faces of survivors at their annual conferences—the relief of recognition, the comfort of shared experience, the gradual rebuilding of identity. One day in particular stands out: in June 2018, when 127 cardiac arrest survivors gathered at our cardiac centre to set a Guinness World Record. Standing in that room, surrounded by people who had each been given a second chance at life, remains my proudest moment as a doctor.

The guide you hold in your hands distils a decade of learning into practical wisdom. It is not written from theory but from the daily reality of supporting thousands of people through one of life's most lethal and disorienting experiences. Paul writes with the authority of someone who has lived this journey and the generosity of someone determined to light the path for others.

Whether you are a survivor seeking to help others, a healthcare professional looking to better support your patients, or someone moved to build a similar community in your own country, this guide will serve you well. The principles within it—authenticity, practical, pragmatic, patience, boundaries, hope—are universal.

Cardiac arrest survival rates are improving. More people are being given second chances. The question is whether we, as a society, will properly support them. This guide is part of the answer.

Professor Thomas Keeble — Consultant Cardiologist, Essex Cardiothoracic Centre; Professor of Cardiology and Circulatory Health, Anglia Ruskin School of Medicine; Founding Trustee, Sudden Cardiac Arrest UK

Acknowledgements

The Trustees of Sudden Cardiac Arrest UK

This guide, and the organisation it describes, would not exist without the dedication of those who have given their time, expertise, and energy to govern, nurture, and grow Sudden Cardiac Arrest UK (SCA UK). They have provided strategic direction, safeguarded our values, and ensured we remain true to our mission.

Paul Swindell — Survivor. Founded SCA UK after a pub meeting with fellow survivors in February 2015, and has led its growth ever since.

Professor Thomas Keeble — Consultant Cardiologist at the Essex Cardiothoracic Centre and Professor of Cardiology and Circulatory Health at Anglia Ruskin School of Medicine. Established the UK's first Care After REsuscitation (CARE) clinic in 2014.

Gareth Cole — One of the original thirteen at the founding meeting. A two-time cardiac arrest survivor who has also survived a stroke, Gareth brings the perspective of someone who knows this journey intimately. An engineer and businessman, he has been instrumental in organising our conferences and events.

Joanna Balgarnie — Survivor. One of the original thirteen at the founding meeting, joining just six months after her cardiac arrest. Brings experience from working with military charities supporting families, and lives the power of peer support—a connection made through the Facebook group led to a medication change that stopped her ICD shocks and restored her driving licence.

Stuart Menzies — Co-survivor and lifesaver. Performed CPR on his wife during her out-of-hospital cardiac arrest in 2016. A retired Police Scotland officer of 30 years, now working part-time in his community. Progressed from member to moderator to trustee, and now leads our moderator team and coordinates our regional meetups.

Charlotte Pickwick — Former trustee. Survivor and NHS Nurse Manager saved by her husband Stuart on Boxing Day 2017. Together they founded Do It For Defib, placing defibrillators and providing CPR training in the Bracknell area.

Our Moderators: The daily work of supporting our community falls to our volunteer moderators—survivors and co-survivors who give their time to welcome new members and maintain a safe space. Our thanks to all past and present moderators: Dawn Saunders, Dave Cleland, Trudy Bass-Chapman, Kate Bradstock, Charlie Dickens, Ingrid Gardner, Jonathan Jenkyn, Chris Solomons, and Fay Judson.

With Thanks To...

SADS UK

Anne Jolly MBE and **John Jolly MBE**

In the early years of Sudden Cardiac Arrest UK, SADS UK was there to support us—funding our first leaflet and distributing it to organisations across the country, covering venue deposits when our meetups outgrew pub corners, and providing a counselling pathway for members who needed professional support.

SADS UK was founded by Anne and John after the sudden death of their sixteen-year-old son Ashley in 1998. From their grief, they built something extraordinary—campaigning for defibrillators in schools, funding research, supporting bereaved families, and lobbying until legislation changed. sadsuk.org.uk

The Essex Cardiothoracic Centre

The Essex Cardiothoracic Centre at Basildon Hospital saved my life in April 2014. But their support did not end there.

From the earliest days of SCA UK, the team at the CTC have been partners in everything we do. They have hosted our conferences, including the 2018 Guinness World Record event that brought together 127 survivors. They have provided clinical expertise, referral pathways, and the credibility that comes from working alongside a centre of excellence. Professor Thomas Keeble, who founded the UK's first dedicated CARE clinic at the CTC in 2014, became a founding trustee of SCA UK and has been instrumental in bridging the gap between clinical care and peer support.

Building relationships with supportive clinicians and hospitals has been essential to SCA UK's development—not just for credibility and referrals, but for grounding our work in clinical reality while maintaining an authentic patient voice. The Essex Cardiothoracic Centre has been the model for what that partnership can look like.

The Resuscitation Council UK

When SCA UK decided to become a registered charity in 2022, the Resuscitation Council UK provided invaluable support—funding the legal work, offering comprehensive advice on charity governance, and guiding us through the registration process. Their belief in the importance of peer support led by those with lived experience gave us both practical help and credibility at a crucial moment in our development.

We are grateful for their ongoing partnership and for their commitment to improving outcomes for everyone affected by cardiac arrest. resus.org.uk

About the Author

Paul Swindell is the founder and chair of Sudden Cardiac Arrest UK.

On 4th April 2014, Paul suffered an idiopathic cardiac arrest at home. His wife Tracy found him, called 999, and performed CPR until paramedics arrived. The medical care that followed was excellent. The support for what came next—the cognitive difficulties, the anxiety, the invisible struggles of recovery—was largely absent. Paul found himself searching online for others who understood, and discovering that such communities barely existed.

In February 2015, Paul arranged the first meetup of cardiac arrest survivors at the Mulberry Bush pub in London. Thirteen people came. On 1st May 2015, he created the Facebook group—ensuring other survivors and their families would not have to face the journey alone.

Over the following years, Paul developed relationships with the resuscitation and cardiac arrest community, working with the Resuscitation Council UK on various initiatives. In 2020, he spoke at the European Resuscitation Council Congress in Manchester (held virtually due to the pandemic)—the first of several ERC presentations.

Paul contributed to the All-Party Parliamentary Group on Defibrillators sessions at Westminster, with his input featured in their subsequent report. In 2023, Sudden Cardiac Arrest UK received the American Heart Association International Collaboration Award, recognising the organisation's contribution to cardiac arrest survivorship globally.

In 2024, Paul worked with the Resuscitation Council UK on the development of their survivorship quality standards, and spoke at the European Resuscitation Council Congress in Athens. He serves as a Patient and Public Involvement and Engagement (PPIE) representative on European Resuscitation Council guidelines, contributing to both the Ethics and Post-Resuscitation Care chapters of the ERC 2025 guidelines. He successfully advocated for the inclusion of "co-survivor" terminology in official medical guidance.

In 2025, Paul spoke at the ERC Congress in Rotterdam, continuing his work to ensure the survivor voice is heard in resuscitation science and policy.

In Memoriam

Fay Judson and **Gwyn Robinson**

Two beautiful ladies who contributed to SCA UK in their own ways.

Fay was a moderator for many years—warm, wise, and dedicated. Gwyn was one of the original thirteen who met in that London pub in February 2015, showing up when the room was still mostly empty.

Both passed away in 2025.

This guide is published in their memory.

Contents

A Note on Terminology

A cardiac arrest is not a heart attack. A heart attack occurs when blood flow to the heart is blocked—painful and serious, but the heart keeps beating. A cardiac arrest is when the heart stops. Without immediate CPR and defibrillation, it is fatal within minutes. Many people—including some in healthcare—confuse the two. This guide is specifically about cardiac arrest: the sudden, catastrophic event that kills most of its victims and leaves survivors facing a recovery journey that few understand.

Throughout this guide, we use the term **co-survivor** to describe anyone directly affected by a cardiac arrest other than the patient themselves: the partner who performed CPR, the child who called the ambulance, the colleague who fetched the defibrillator, the family members living with the aftermath. They did not have the cardiac arrest, but they survived it too—in a different way. The term is now recognised in European Resuscitation Council guidelines, and we believe it better captures their experience than "family member," "bystander," or "carer." The Co-Survivor Model chapter explores this concept in depth.

Introduction: Why Peer Support Matters

Something happens in the weeks after a cardiac arrest that medicine struggles to address. The acute crisis is over. The interventions have been made. The medications have been prescribed. If they are lucky, cardiac rehabilitation appointments have been scheduled. And yet.

Survivors find themselves asking questions that clinicians cannot answer: Will I ever feel like myself again? Why can I not remember simple words? Is it normal to feel this afraid? Why does my family treat me differently now? Am I going mad?

Meanwhile, the people who performed CPR—often family members who watched someone they love die and brought them back—are sent home with a handshake and perhaps a leaflet. Their trauma is invisible to a system focused on the patient.

This is the gap that peer support fills. Not as a replacement for clinical care, but as its essential complement. Survivors need to meet other survivors. They need to hear "I felt that too" from someone who actually has. They need to see people thriving years after an event they were told should have killed them. They need help finding their "new normal"—a phrase that captures so much in just two words.

New members often arrive with "what the hell just happened?" still ringing in their ears. They are confused, frightened, and feeling abandoned by the system that saved them. When they find others who have stood at the same edge of the abyss, something shifts. We just "get it." The support offered builds confidence and hope for healing that was missing before. It often feels like a group hug is taking place.

Sudden Cardiac Arrest UK began with a meeting in a pub in February 2015, followed by a Facebook group two months later. Eleven years on, it has grown into what is, to our knowledge, the world's largest national cardiac arrest survivorship organisation, with over 4,000 members across the United Kingdom. We have worked with the Resuscitation Council UK to develop their quality standards for survivorship, contributed to European Resuscitation Council guidelines (including helping establish the concept of "co-survivors" in medical literature), achieved a Guinness World Record by bringing together 127 survivors in one place, and received the American Heart Association International Collaboration Award in 2023.

But none of that mattered as much as the first time a terrified new survivor posted at midnight, overwhelmed and alone, and woke to find three people had already responded with their own stories.

This guide captures what we have learned—not as a template to copy, but as a foundation to build upon. Every country and culture will need to adapt these principles to their own context. What works in the UK may not translate directly to Germany or Spain or Poland. But the core insight remains universal: survivors helping survivors works, and the world needs more of it.

Cardiac arrest strips away three things that matter deeply to human beings: narrative coherence ("this makes sense"), identity continuity ("I am still me"), and future visibility ("people like me have a future"). Medicine treats the event; peer support treats the meaning of the event. When survivors meet others who have walked the same path and rebuilt their lives, they gain something no clinician can provide—proof that recovery is possible, and a map drawn by people who have actually made the journey.

Who This Guide Is For

This guide is written for:

- **Solo founders:** Survivors or co-survivors who feel the urge to create something but do not know where to start
- **Small grassroots groups:** Informal networks already supporting each other who want to grow or formalise
- **Patient-led organisations:** Groups thinking about governance, partnerships, or sustainability
- **Healthcare professionals:** Clinicians who want to understand what patient-led peer support looks like, or who are considering supporting an initiative led by survivors or co-survivors

This is **not** a clinical manual, a commissioning framework, or a fundraising guide. It is a practical handbook written by someone who has done this work, made mistakes, learned from them, and wants to help others avoid reinventing every wheel.

For Healthcare Professionals: This guide describes a patient-led peer support model that complements, but does not replace, clinical care. We welcome referrals and collaboration where roles are clear and independence is preserved. Peer support networks do not provide medical advice, clinical decision-making support, or therapeutic interventions. What they offer is something different: the lived understanding of people who have been through what your patients are going through. If you are a clinician considering supporting or initiating a peer support network, the ideal is to find a survivor or co-survivor willing to lead—but we recognise this is not always possible. Where healthcare professionals must take the founding role, the goal should be to cultivate leadership by those with lived experience as quickly as possible, stepping back as authentic voices emerge.

On evidence: Peer support is not evidence-free; it is evidence-adjacent. It captures realities that clinical trials are not designed to measure—the 2am fears, the identity shifts, the family strain, the slow rebuilding of confidence. Randomised controlled trials measure what can be measured. Peer support addresses what cannot easily be quantified but matters enormously to recovery. The two approaches are complementary, not competing.

The field of cardiac arrest survivorship is growing. Research from the UK, Europe, North America and elsewhere is building our understanding of post-arrest quality of life, cognitive outcomes, and psychological needs. The International Liaison Committee on Resuscitation (ILCOR) now includes survivorship in its scientific reviews. The European Resuscitation Council's 2025 guidelines include dedicated sections on post-resuscitation care and, for the first time, recognise "co-survivors" as a population deserving attention. A 2025 ERC survey of survivor organisations found that peer support, informational materials, and research collaboration are the core activities of the handful of organisations that exist worldwide—and that more are desperately needed. Peer support networks exist within this evolving landscape—not as an alternative to evidence-based care, but as a patient-led complement to it.

If you are still in acute recovery: This work can wait. If the world still feels unreal, if you are still struggling to process what happened—bookmark this guide and come back when you are ready. Your own recovery comes first. The community you might build will still need building in six months or a year. There is no rush.

You will get things wrong. We did. Some posts will land badly. Some moderation decisions will be imperfect. Some members will leave unhappy. That does not mean you are failing. It means you are doing real work with real people in messy circumstances. The goal is not perfection; it is showing up, learning, and getting better over time.

Quick Start: If You Read Nothing Else

If you are eager to begin and find long documents overwhelming, here is what you need to know to get started. Everything else in this guide is refinement—important, but not essential on day one.

The Absolute Minimum

1. **Choose a platform where your members already are.** For many demographics, this is Facebook. Create a private group. You can always add other platforms later.

2. **Find one other person to help you.** You cannot moderate alone. Even if it is just a trusted friend or fellow survivor who can cover when you are unavailable—you need backup from day one.

3. **Write simple rules.** At minimum: Be kind. No medical advice—members share experiences, not recommendations. What is shared here stays here. No unsolicited direct messaging. You can refine these as you grow.

4. **Set joining questions.** Ask people to explain their connection to cardiac arrest before you approve them. This filters spam and ensures everyone has lived experience.

5. **Start posting.** Share your own story. Ask a question. Create something for people to respond to. Empty groups stay empty.

6. **Have a crisis plan.** Know what you will do if someone posts about self-harm. Have your local crisis line number ready. See Appendix C for a full protocol.

The Mindset

- Start small and simple. You do not need a logo, a website, or funding to begin.
- Your job is to light a fire and keep it burning. In the early days, that means showing up consistently, welcoming every new member, and creating conversation.
- Grow slowly. Ten engaged members matter more than a hundred silent ones.
- You will make mistakes. That is fine. Learn and continue.
- Success means building something that can thrive without you. If it outgrows you, that is not failure—it is the goal.

What Can Wait

- A website
- Formal charity registration
- Healthcare partnerships
- Merchandise or branding

- Perfection

Now go start. Come back to the rest of this guide when you need it.

Before You Begin: Foundations

Who Should Start This?

The short answer: someone with lived experience. The credibility of a peer support network comes from authentic voice, and that authenticity cannot be manufactured or delegated.

This does not mean healthcare professionals cannot be involved—they absolutely should be. But a network founded and led by clinicians will always feel different from one shaped by survivors themselves. Patients can tell the difference, even when they cannot articulate why.

The ideal founder is someone who:

- Has survived a cardiac arrest themselves, OR has performed CPR on someone they love
- Has had enough time to process their experience (typically at least a year, often longer)
- Feels a genuine desire to help others, not just to talk about their own experience
- Has the emotional resilience to hear difficult stories without being destabilised
- Can commit time and energy over years, not months

That last point about commitment matters more than people expect. Building a community is not a project with an end date. It becomes part of your life.

A word about fear: Many potential founders hesitate because they worry about liability. What if someone in the group harms themselves? What if advice shared by members turns out to be wrong? What if something goes badly and you get blamed?

These fears are common but often overstated. Peer support founders typically overestimate their personal liability and underestimate the risk of *not* providing support at all. You are not providing medical advice, clinical care, or professional services. You are creating a space where people with shared experience can talk to each other. Sensible boundaries, clear disclaimers, and honest communication about what you are (and are not) protect you far more than most people realise. The greater risk is that survivors continue to feel alone because no one was willing to start something.

This is not legal advice—if you have specific concerns, consult a lawyer in your jurisdiction. But do not let generalised fear stop you from doing something that could genuinely help people.

What you are NOT responsible for:

- Members' medical outcomes or treatment decisions
- Providing diagnosis, therapy, or clinical care
- Preventing all possible harm
- Fixing members' lives or solving their problems

- Being available around the clock

What you ARE responsible for:

- Setting and enforcing reasonable boundaries
- Signposting to professional help when needed
- Creating a space that is as safe as you can reasonably make it
- Looking after yourself so you can continue

You are responsible for reasonable care, not for outcomes you cannot control.

When NOT to start: Not every impulse to create a peer support network should be acted upon. Consider waiting or reconsidering if:

- You are still in acute recovery yourself (typically less than a year post-arrest)—your own healing needs to come first
- Your primary motivation is processing your own experience rather than supporting others—a therapist or existing peer group may be more appropriate
- An excellent network already exists for your target population—joining and strengthening that may be more valuable than fragmenting the community
- You cannot find at least one other person willing to share the load—solo founding without backup is a path to burnout
- You are hoping this will fix something in yourself—peer support leadership is rewarding, but it is not therapy

None of these are permanent disqualifications. They are reasons to pause, reflect, and perhaps return when circumstances have changed.

Core Principles

Before deciding on scope and structure, establish your foundational principles. These should guide every decision you make:

Free and accessible: Community and resources should be free. Always. Cardiac arrest does not discriminate by income, and neither should access to peer support. The moment you put up a paywall—even a small one—you exclude the people who may need you most.

Low barriers to entry: Every obstacle you create will stop someone from joining. Registration forms, approval processes, complicated platforms—each one filters out people who might have benefited. Make it as easy as possible to participate. But low barriers to entry does not mean low standards for safety—you will still need moderation, guidelines, and gatekeeping to protect your community. The goal is to make joining simple while keeping the space safe.

Designed for your actual members: Cardiac arrest affects people of all ages, but the demographic skews older. Many of your members will not be IT-literate. They may struggle with technology, feel intimidated by online platforms, or access everything via a mobile phone with a small screen. Design for them, not for digital natives. If your grandmother could not figure out how to join, it is too complicated.

Recognise that experiences differ: A 35-year-old survivor navigating career impact and young children faces different challenges than a 70-year-old concerned about independence and family burden. Women and men often present differently and seek support differently. Your community will contain all of these people. You cannot address every specific need—that is not the role of peer support—but you can create space where different experiences are acknowledged and members can find others whose circumstances resemble their own.

Young adult survivors face distinct challenges that deserve explicit acknowledgment. Cardiac arrest in your twenties or thirties disrupts life at a formative stage: careers derailed before they are established, dating complicated by ICDs and health history, friendships with peers who cannot relate, fertility concerns for those who have not yet had children, and the particular weight of facing mortality when you expected decades ahead. Social media presence becomes complicated—do you share this part of your life publicly? Young survivors may feel isolated in communities where most members are decades older. If your network includes young adults, consider how to create connection points for them.

Commonly avoided topics: Some concerns are near-universal among survivors but rarely discussed because they feel embarrassing or too personal:

- **Return to sexual activity** is a significant concern that many survivors struggle to raise, even with clinicians. Fear of triggering another arrest, ICD-related concerns about physical contact, medication effects on libido and function, psychological barriers after trauma, and changed relationship dynamics all play a role. If members raise this topic in your community, treat it as the legitimate health concern it is.
- **Driving restrictions and licensing processes** cause enormous anxiety and practical hardship. The bureaucracy, the waiting, the uncertainty, and the loss of independence are genuinely distressing. Members often need both practical information and emotional support through this process.
- **Financial hardship** following cardiac arrest is common but rarely discussed. Lost income during recovery, career damage or job loss, insurance complications, and medical costs (in systems without universal healthcare) can be devastating. Acknowledging this reality—and connecting members facing similar challenges—is valuable even when you cannot solve the underlying problems.

Create space for these topics to emerge. Sometimes simply acknowledging that "many survivors worry about X" gives permission for members to share.

Be aware of who you are not reaching: Cardiac arrest does not discriminate, but peer support communities often end up serving a narrower demographic than the population they aim to help. Our membership skews older and female; other communities may have different patterns. Consider who might be missing: people with limited fluency in your community's language, those without internet access, communities where health discussions carry stigma, people whose work schedules prevent participation, those who do not see themselves reflected in your existing membership. You will not solve all these barriers, but being aware of them helps. Small adjustments—varying meetup times, translating key materials, actively welcoming members from underrepresented groups—can widen your reach over time.

Your First Decision: Scope and Audience

Before you create anything, decide who you are trying to reach. This seems obvious, but many networks fail because they never clearly defined their audience.

Questions to consider:

- Survivors only, or co-survivors too? (We strongly recommend including both from the start—see The Co-Survivor Model chapter)
- National scope, regional scope, or local?
- Language considerations—will you operate in one language or multiple?

There is no wrong answer, but there is a wrong approach: trying to be everything to everyone from the start. Begin focused. You can always expand later.

Connect with your national resuscitation council: Most countries have a resuscitation council or equivalent body that coordinates cardiac arrest guidelines and education. Reaching out early—even before you launch—can provide credibility, potential referral pathways, and connection to the broader resuscitation community. They may not be able to help directly, but they will know who can.

A note on cultural context: This guide is written from a UK perspective, where relatively open discussion of health experiences is culturally acceptable. In some cultures, discussing trauma, death, or medical experiences publicly is less normalised or may carry stigma. If you are establishing a network in such a context, the open sharing model may need adaptation—perhaps starting with educational content or smaller private gatherings before expecting members to share openly online. The principles remain the same; the implementation may differ.

If you are outside the UK, pause and consider:

- Which platforms are dominant in your country? (Facebook is not universal)
- What are local attitudes to disclosing trauma and health experiences publicly?
- What legal expectations exist around online moderation, data protection, and liability?
- Is patient advocacy led by those with lived experience culturally expected, or will you face resistance from medical establishments?
- Are there existing organisations you should partner with rather than duplicate?

Do not assume that what worked in one country will translate directly. Adapt the principles; do not just copy the implementation.

Staying Focused: Peer Support Is Not Everything

Many survivors have an immediate and understandable reaction after their cardiac arrest: they want to ensure this does not happen to anyone else. They want to raise awareness, fundraise for defibrillators, campaign for CPR training in schools, and put AEDs in every public place. This impulse is admirable—and acting on it can be deeply rewarding and beneficial for their own recovery.

But it is not what we do.

There are many organisations focused on awareness, prevention, and defibrillator placement. There are very few focused on what happens to survivors and their families after the event. That is our space. That is where we concentrate our energy. We focus on lived experience and supporting those affected—not on the broader public health campaign.

This distinction matters because trying to do everything dilutes your effectiveness at everything. A peer support network that also runs awareness campaigns, fundraises for equipment, lobbies government, and trains the public in CPR will struggle to do any of those things well. And the core mission—supporting survivors and co-survivors—will suffer.

When members come to us wanting to "give back" through awareness work or defibrillator fundraising, we celebrate their energy and redirect them to organisations better placed to help. In the UK, this might include the British Heart Foundation, the Resuscitation Council UK, or local community defibrillator schemes. Every country has equivalent organisations. We are not gatekeeping—we are helping members find the right outlet for their passion while we focus on what we do best.

Define your scope early. Protect it. Refer outward generously. Your value comes from depth in your chosen area, not breadth across everything cardiac-related.

The Minimum Viable Network

What do you actually need on day one? Far less than you think.

Essential:

- A platform where people can connect (more on this below)
- Clear guidelines for participation
- Someone to share moderation with you
- A way for people to find you (even if just word of mouth initially)
- A way to contact members independently of your platform (even a simple email list)

That last point matters more than people realise. If you build your community entirely on Facebook (or any platform you do not control), you have no way to reach your members if the platform changes, your group is suspended, or you need to migrate. Start collecting email addresses early—even just through a simple sign-up form. This is your insurance policy.

As noted in the Quick Start, you do not need a website, formal structure, healthcare partnerships, funding, or a logo to begin. Do not let the absence of "professional" infrastructure stop you from starting. Some of the most valuable peer support happens in the most humble settings. You can build the scaffolding as you grow.

Data Protection and Privacy

A brief but important note: you will be handling sensitive personal information. Health data is among the most protected categories under data protection law (GDPR in Europe, similar frameworks elsewhere). If you are outside Europe, check your local laws regarding personally identifiable information (PII)—most countries have similar requirements for health data, even if the specific regulations differ. You need to think about this from the start, even if you keep it simple.

General principles:

- Only collect information you actually need
- Be clear with members about what you collect and why
- Get explicit permission before storing personal data
- Keep whatever you store secure
- Have a plan for how long you keep data and when you delete it

Minimise your responsibility: Where possible, use platforms that handle data protection for you. If you run a Facebook group, Facebook is the data controller for most of that data—not you. This is actually an advantage of using established platforms rather than building your own. The moment you start collecting email addresses, building spreadsheets of member information, or running your own database, you take on significant legal responsibilities.

Email lists and newsletters: If you build an email list, use a reputable service (Mailchimp, Mailerlite, etc.) that handles consent and unsubscribe requirements properly. Do not just collect emails in a spreadsheet and send from your personal account—this creates both legal risk and security vulnerabilities.

What you might need to store:

- Contact details for volunteers and committee members
- Event registration information
- Research participant data (if you collaborate on studies)
- Donation records (for charity compliance)

For each category, ask: Do we need this? How will we keep it secure? When will we delete it? Who has access?

This is not legal advice—consult appropriate professionals for your jurisdiction. But do not ignore it. A data breach involving health information would be devastating for member trust and potentially for your organisation's survival.

Free Tools for Getting Things Done

You do not need a budget to run a peer support network professionally. Many powerful tools are available free—for documents, design, communication, scheduling, video meetings, and even websites. Most peer support networks can operate entirely on free tools indefinitely.

The principle is: start free, stay free as long as possible, and only pay for tools when the free version genuinely cannot do what you need. See Appendix F for a detailed list of free tools we recommend.

Phase 1: Lighting the Fire (Year 1)

The early days, months, and years of building a peer support community are like lighting a fire. You need that initial spark—the moment you decide to create something. Then you add kindling: your first few members, the early conversations, the tentative sharing of stories. You nurture it carefully, shielding it from winds that might extinguish it, feeding it with attention and fuel until it grows into something that provides warmth and comfort to everyone who gathers around it.

But here is the crucial thing about fires: they need constant attention to stay alight. Unless someone is nursing and cultivating the community, it can easily die. Especially in those early days, you cannot light it and walk away. The fire needs you.

Choosing Your Platform

The platform matters less than the accessibility. We began with Facebook because it was free, widely used, and required little technical skill to set up. A decade later, we are still primarily on Facebook—not because it is ideal, but because it is where our members are.

Remember your demographic. A significant proportion of your members will access everything via mobile phone. Many will be older and less comfortable with technology. Whatever platform you choose must work well on small screens and be intuitive enough that someone who did not grow up with computers can navigate it.

Understanding your likely membership helps with platform and communication choices. Our Facebook group membership skews older (peak ages 45–64) and predominantly female (64%). The gender split is notable given that cardiac arrest itself is more common in men—it likely reflects that co-survivors (often partners) join in significant numbers, and that women may be more likely to seek peer support. This demographic profile reinforces our choice of Facebook over platforms like Discord that skew younger.

Options to consider:

Facebook Groups

Pros: Free, familiar to most users including older demographics, good moderation tools, members can find you through search, notifications keep people engaged, works well on mobile.

Cons: Algorithm changes affect visibility, some people refuse to use Facebook, younger demographics may prefer other platforms, data privacy concerns.

A note on Facebook structure: Facebook offers both Groups and Pages, and they serve different purposes. Our groups are closed private groups—people can search and find them, but they cannot see the content unless they are a member. This creates a safe space for vulnerable sharing. Think of it as the community that meets inside the village hall, with gatekeepers on the doors to ensure everyone is safe and comfortable.

We also have Facebook Pages, which are public—anyone can see the content. We use these to disseminate information to the wider world: news, resources, awareness campaigns. Think of this as the noticeboard outside the village hall. Both serve important functions, but they are not the same thing.

WhatsApp/Signal/Telegram Groups

Pros: More immediate and personal, good for smaller groups, end-to-end encryption available, very mobile-friendly.

Cons: Harder to search history, can feel overwhelming with high message volume, limited moderation tools, phone number sharing required.

Dedicated Forums or Platforms

Pros: Full control over features and data, more professional appearance, no algorithm interference.

Cons: Requires technical setup and maintenance, another login for users to remember, harder to build initial critical mass, often less intuitive for older users.

Discord

Pros: Multiple channels for different topics, good moderation tools, younger demographic familiar with it.

Cons: Steep learning curve for older users, gaming associations may seem inappropriate for medical community, interface can be overwhelming.

Paid Community Platforms (Skool, Mighty Networks, Discourse, Circle)

Pros: Purpose-built for communities, professional features, better control over member experience, no algorithm interference, often include course/content hosting.

Cons: Monthly costs (typically $30–200+ or equivalent), another login for users, harder to build critical mass when members must leave familiar platforms, may be overkill for starting out.

These paid platforms are worth considering as you grow and if budget allows, but we would not recommend them for starting out. The cost creates pressure, and the unfamiliarity creates barriers. Start free, prove the concept, then consider upgrading if the limitations of free platforms become genuinely problematic.

Our advice: start where your potential members already are. You can always add additional platforms later. The worst outcome is choosing a platform that creates barriers to participation.

A word of caution about platform dependency: Building your community on Facebook (or any platform you do not control) means accepting that the rules can change without warning. Algorithm changes can reduce your visibility overnight. Features you rely on can be removed. Policies can shift in ways that affect how your community operates. We have seen this repeatedly over the years. There is no perfect solution—the alternatives each have their own drawbacks—but be aware that you are building on rented land. Maintain an email list or other direct contact method so you can reach members if you ever need to migrate. Periodically save or archive particularly valuable threads and discussions—the collective wisdom your community generates is worth preserving, and you cannot assume it will always be accessible on the platform. And do not assume today's functionality will exist tomorrow.

If your platform fails: Have a plan for how you will reach members if your primary platform becomes unavailable—whether temporarily (outage) or permanently (account suspension, policy change, platform closure). At minimum:

- Maintain an email list independent of your main platform (even a simple Mailchimp or Google Forms sign-up)
- Ensure at least two people have access to that list
- Have a backup communication channel ready (a WhatsApp broadcast list, a secondary Facebook group, a simple website with contact information)
- Know how you will tell members where to go—if your group disappears, how will they find you?

You may never need this plan. But if you do need it and do not have it, years of community building could evaporate overnight.

Creating Guidelines and Moderation

A blunt warning: If you are not prepared to read about fear, cognitive damage, relationship breakdown, grief, and death on a regular basis, this role will hurt you. Moderation in a cardiac arrest community means exposure to raw human suffering. Most of the time it is manageable; sometimes it is not. Know this before you commit, and build support systems before you need them.

Written guidelines prevent arguments and make moderation decisions easier. See Appendix A for our complete group rules—feel free to adapt them for your context.

Key elements to include:

- What the group is for (peer support, shared experience, mutual encouragement)
- What it is not for (medical advice, product promotion, fundraising appeals, off-topic discussions including politics, religion, and non-evidence-based complementary medicines)
- Joining criteria (we require answers to specific questions—this filters out spam and ensures everyone has lived experience)
- Expectations for behaviour (kindness, respect, confidentiality)

- Rules about direct messaging (protecting vulnerable members from unwanted contact)
- Consequences for violations (warning, then removal)

Joining questions: Facebook allows you to set questions that people must answer when requesting to join. We use three:

1. *What is your reason for wanting to join this group?* (Multiple choice: I am a UK SCA survivor / I am a partner or close family (co-survivor) of a UK SCA survivor / I am a friend or carer (key supporter) of a UK SCA survivor / I know someone who died from an SCA in the UK / None of the above)

2. *Without sharing personal details, briefly explain the cardiac arrest event that prompted your request to join us.*

3. *How did you find out about Sudden Cardiac Arrest UK?*

These questions serve multiple purposes: they filter out spam accounts, help you understand who is joining and why, confirm the person has a genuine connection to cardiac arrest, and give you useful information for welcoming them appropriately. Make clear in your group description that all questions must be answered—incomplete requests get declined.

Note: Adapt these questions to your context. Replace "UK" with your country or region. The structure matters more than the specific wording.

Group description: Your group description is often the first thing potential members see. It should clearly explain who the group is for, what you offer, and what you do not cover. Be explicit about boundaries—if you do not support bereaved members in your main group, say so and point them to appropriate alternatives. Include links to sister groups or partner organisations where relevant. Our description also includes basic information about what sudden cardiac arrest is, because many people still confuse it with heart attack.

Membership requests: Be prepared to review requests carefully. Many will be incomplete or from people who do not fit your criteria. Look at profiles for clues—location, interests, other groups they belong to. Do not be afraid to decline requests that seem suspicious; roughly half of ours do not make it through. If you are unsure, message the person directly to ask for their story, or seek a second opinion from another moderator.

Red flags when screening requests:

- Brand new profiles with little or no history (created days or weeks ago with minimal activity)
- Profile pictures that look like stock photos or AI-generated images
- Facebook Pages or business accounts rather than personal profiles—you cannot verify who is actually behind them, and they may represent multiple people
- Profiles that do not match the story given in their answers (claims to be UK-based but profile suggests otherwise)
- Vague or copy-pasted answers that do not sound like a real person's experience

- Incomplete answers despite clear instructions

None of these are automatic disqualifications, but they warrant closer inspection. When in doubt, message the person directly. Genuine applicants will respond; suspicious ones often do not.

Timing matters: Try to process membership requests promptly—ideally within 24 hours. A warm welcome posted at a time when people are active (early morning, lunchtime, evening) gets more engagement and helps new members feel seen.

Moderation is more demanding than people expect. You will need to:

- Review membership requests (daily, ideally)
- Monitor discussions for guideline violations
- Handle disputes between members
- Remove inappropriate content
- Support members who post in crisis
- Manage your own emotional response to difficult content

A note on removal: In general, groups like ours are largely self-managing—most posts are supportive and conflicts are rare. Our policy is to give people the benefit of the doubt, since everyone is at a different stage in their recovery and it can be difficult to convey thoughts precisely in writing. We rarely remove members. However, if someone is intentionally causing harm or distress, appropriate action must be taken.

Why the direct messaging rule matters: The rule against unsolicited direct messaging is not bureaucracy—it exists because vulnerable communities can attract unwanted attention. We learned this when a member who appeared legitimate and made no inappropriate public posts was privately messaging women in the group. The messages started as innocent enquiries but turned out to be inappropriate. It only came to light when a message to an admin raised suspicions.

This is rare, but worth being aware of. The direct messaging rule gives you grounds to act if something similar happens, and encourages members to report private contact that makes them uncomfortable. Trust your instincts when something feels off.

Admin permissions and account security: On platforms like Facebook, there is a crucial difference between "moderator" and "admin" roles. Admins have full control—they can remove other admins, change group settings, or even transfer ownership. Moderators can manage posts and members but cannot take over the group.

Protect admin access carefully:

- Only grant admin permissions to a small number of trusted people (trustees, long-standing volunteers you know well)
- Moderators should have moderator permissions, not admin—this is sufficient for their daily work

- Use multi-factor authentication (MFA) on all admin accounts without exception
- If an admin's personal account is compromised by hackers, they could use that access to hijack your group

This is not about distrusting your moderators. It is about limiting damage if something goes wrong—whether through malice (rare) or a hacked account (more common than you might think). A hostile takeover of your group, even an accidental one, could undo years of work overnight.

A private moderators group: We maintain a separate, private group just for moderators. This is where we discuss difficult membership requests, share concerns about particular posts or members, coordinate responses to sensitive situations, and share resources and guidance. Having this space means moderators can think out loud and seek advice without those discussions being visible to the main community. It also builds team cohesion—moderating can feel isolating, and having a space to talk with others doing the same work helps.

Anonymous posts: Facebook allows members to post anonymously. We permit this, but only when used judiciously—for genuinely sensitive topics where someone might not feel comfortable attaching their name. Openness is central to what we do; everyone in the group understands what others are going through, and posting openly usually generates more personal and supportive responses. When members request anonymous posting for content that does not warrant it, we decline the post with an explanation and invite them to repost under their name.

Finding Your First Members: The Kindling

The first fifty members are the hardest. These are your kindling—without them, the spark goes out. Here is how we grew:

- **Personal networks:** Some survivors connect with others through cardiac rehabilitation or hospital support groups. Others find each other through online searching. Ask anyone you know who has been through this to join and invite others.
- **Healthcare professionals:** Even without formal partnerships, individual doctors, nurses, and physiotherapists often want to help patients connect. Give them something to share.
- **Existing organisations:** National heart charities, resuscitation councils, and patient advocacy groups may be willing to mention you in newsletters or social media.
- **Media:** Local human interest stories about cardiac arrest survival can mention the group. Every article brings a wave of new members.
- **Search optimisation:** Make sure your group name includes words people actually search for ("cardiac arrest survivor" rather than a clever acronym).
- **Gentle outreach:** When you see someone from your country posting about their cardiac arrest experience in another group or forum—on Facebook, Reddit, or elsewhere online—consider leaving a polite comment mentioning that your community exists and they might find it helpful. Be respectful: you are a guest in someone else's space. Do not spam or recruit aggressively. A simple "If you're looking for peer support, you might also

be interested in [your group]" is enough. This remains one of our most effective ways of finding members who need us but do not know we exist.

Be patient. Growth is not linear. You may go weeks with no new members, then gain thirty in a day after someone shares a post. The important thing is to be there, consistently, for whoever arrives.

Establishing Culture Early

The tone you set in the first few months will define your community for years. This is not something you can easily change later.

Key principles we established early:

- **Warmth first:** Every new member receives a genuine welcome. In the early days, we wrote a personalised introduction post for each person who joined. As the community grew, this became unsustainable, and we moved to a template welcome message—but we designed it to still feel warm and to provide essential starting information (where to find resources, how to introduce yourself, key guidelines). Crucially, our existing members engage with these welcome posts—responding, offering encouragement, sharing their own experiences. This creates a culture of warmth that new members feel immediately. They see they are joining something alive, not an empty room.
- **No medical advice:** Members share experiences, not recommendations. "This is what worked for me" is fine. "You should try this medication" is not. However, *patient advocacy* is different from medical advice—helping someone navigate the system ("Ask your doctor about a referral to cardiology" or "Request a copy of your discharge summary") empowers them without playing doctor. Encourage members to advocate for themselves and each other.
- **Honesty over toxic positivity:** Recovery is hard. Pretending otherwise helps no one. Members are allowed to express fear, anger, grief, and frustration.
- **Respect for different paths:** Some survivors return to full activity. Others do not. Some embrace their ICDs. Others struggle. All experiences are valid. This includes members with permanent limitations from hypoxic brain injury or other complications—not everyone will "thrive" in the conventional sense, and they and their carers need space too.
- **The invisible stuff matters:** Cognitive difficulties, fatigue, anxiety, and relationship strain are often dismissed by medicine but dominate survivors' lives. Fatigue alone is the number one issue reported after cardiac arrest, yet it is rarely addressed in clinical follow-up. Validating these experiences is a core function of peer support. Financial stress also belongs here—medical bills, insurance battles, lost income, and career disruption are legitimate topics for peer support, even if moderators cannot solve them.

Stimulating Engagement: Feeding the Fire

A community where no one posts is not a community—it is an empty room. Especially in the early days, you need to actively stimulate engagement. Do not wait for members to start conversations; start them yourself.

Remember that many of your members will be passive participants—"lurkers" who read everything but rarely post. This is not a problem to solve; it is normal and healthy. These members benefit enormously from the discussion even without contributing directly. They see that they are not alone in their experiences. Your job is to ensure there is always something for them to read.

Low-barrier engagement tactics:

The key is making it easy for people to participate. Not everyone is ready to share their story or ask a vulnerable question. But almost anyone can click a button or type a single word.

- **Polls:** These are gold for engagement. People can participate with a single tap. "How many years since your arrest?" "What helped you most in the first month?" "Tea or coffee?" Even trivial polls build the habit of participation.
- **Simple questions:** "What's one thing you wish you'd known earlier?" "Where are you joining us from?" "What's getting you through today?"
- **Memes and light content:** Not everything has to be serious. Appropriate humour builds community. A meme about ICD airport alarms or the absurdity of cardiac rehabilitation exercises can generate comments and shares.
- **Anniversaries and milestones:** "Who's celebrating an arrest anniversary this month?" gives people a reason to share.

Poll best practices:

We have learned some things about polls the hard way:

- **Keep options limited:** Too many choices overwhelm people. Five or six options maximum.
- **Be careful with "add your own option":** If you allow people to add options, you will end up with ten variations of the same answer. Better to keep it controlled and ask for additional context in comments.
- **Use comments for nuance:** "Vote above, then tell us more in the comments" captures both the quick engagement and the richer stories.

The Co-Survivor Model

This deserves its own chapter because it may be the most important thing we have learned.

When someone has a cardiac arrest, the medical system focuses on the patient. Rightly so—they nearly died, after all. But it creates a blind spot. The person who performed CPR, who watched their loved one die and brought them back, who waited in the hospital not knowing if this was the end—that person receives almost no support.

We call these people co-survivors. The term matters. "Family member" or "carer" or "lay rescuer" does not capture what they have been through. They did not just witness a cardiac arrest—they survived it too, in a different way.

Defining Co-Survivors

We define co-survivors broadly: anyone present at a resuscitation event (irrespective of outcome) and those directly affected by the survivor's ongoing journey. This includes:

- Partners, family members, and friends who witnessed the arrest
- Bystanders who performed CPR
- Those who called emergency services or fetched the defibrillator
- Family members living with the ongoing impact of a survivor's recovery
- Those who participated in a resuscitation where the patient did not survive (for support processing the resuscitation experience itself—see the note on bereavement below)

The common thread is trauma related to the resuscitation event and its aftermath.

A note on bereavement: Co-survivor support and bereavement support are related but distinct. Someone who performed CPR on a stranger who did not survive needs help processing that traumatic experience—the questions about whether they did enough, the images they cannot forget, the weight of having tried. That is co-survivor support. But if that person or a bereaved family member needs ongoing help with grief—the long journey of loss, the anniversaries, rebuilding life without someone—that is bereavement support, which requires specialist skills and resources. A peer network founded by survivors can authentically offer the former; the latter should be signposted to dedicated bereavement organisations. Being clear about this boundary serves everyone better.

Why Include Co-Survivors?

- **Their trauma is real:** Research increasingly shows that lay rescuers experience PTSD at rates comparable to emergency service personnel. Family members report lasting psychological impact.
- **They have unique insights:** Co-survivors notice things about recovery that patients cannot see. They watch the cognitive changes, the personality shifts, the hidden struggles.

- **They need peer support too:** Just as survivors benefit from meeting other survivors, co-survivors benefit from meeting others who have performed CPR or watched a loved one collapse.
- **It helps relationships:** Cardiac arrest strains marriages and families. When both partners have access to peer support, both benefit.

An emerging model for lay rescuer support: Recognition that civilian CPR providers need psychological support is growing. In Essex, UK, the RESCQ project is piloting a structured support pathway for lay responders, developed in partnership between the Essex Cardiothoracic Centre, air ambulance services, ambulance trust, and SCA UK. Paramedics register responders at the scene, providing immediate access to resources addressing psychological impact. This model—ensuring support reaches people before they develop lasting trauma—may expand nationally and could inform similar initiatives elsewhere.

Implementing the Model: Our Structure

We did not start with two groups. In the beginning, everyone was together—survivors, partners, family members, anyone affected. It was simpler, and when the community was small, it worked.

But as we grew, the limitations became apparent. We started receiving requests from bystanders who had performed CPR on strangers. Bereaved family members found us, looking for connection with others who understood. And we noticed that some conversations were difficult to have in a mixed space—co-survivors asking questions about what to expect, sharing fears about their loved one's recovery, processing trauma that survivors might find distressing to witness. The reverse was also true: survivors needed space to discuss experiences without worrying about how their words might land with someone whose person did not survive.

The separate co-survivor space emerged from this experience. We did not know to call it that at the time—the terminology came later. But the need was clear: both groups deserved dedicated attention, and mixing everything together was serving neither as well as it could.

This structure requires capacity. Running two communities means more moderation, more coordination, clearer boundaries. If you are just starting out, begin with one group. As you grow and begin to see the tensions described above, you will know when the time is right to create separate spaces. The co-survivor model is an evolution, not a starting point.

That said, this was our journey—it does not have to be yours. If you have enough initial kindling to light two fires from day one (perhaps you are working with a hospital that sees both patients and families, or you already have a core group of co-survivors ready to lead), there is no reason not to start with separate spaces. The key question is whether you have the people to sustain both communities from the beginning. If you do, starting with clear separation may actually be easier than splitting later.

Our current structure:

Sudden Cardiac Arrest UK — focused on the survivor's journey. This is for people who have survived a cardiac arrest themselves. Co-survivors are welcome—sometimes they join while the survivor is still in hospital—but the primary focus remains on the survivor experience. We do not accept bereaved members here, because encountering stories of those who did not survive can be deeply distressing for people still processing their own near-death experience.

Chain of Survival UK — focused on the co-survivor's journey. This is for anyone present at a resuscitation event or directly affected by a survivor's ongoing recovery. Crucially, we welcome those who witnessed or participated in a resuscitation regardless of outcome—including cases where the patient did not survive. However, this is not a bereavement support group. The focus is on helping people process the traumatic experience of the resuscitation itself: What happened? Did I do enough? Was the person in pain? Did I hurt them? These questions haunt co-survivors whether or not the patient survived, and connecting with others who have stood in that same moment of crisis can help. For ongoing bereavement support—the grief journey itself—we signpost to specialist bereavement organisations better equipped to meet that need. The shared experience of witnessing or responding to a cardiac arrest connects people regardless of outcome, but we are clear about the boundaries of what peer support can provide. Survivors are welcome here too, but the primary focus is the co-survivor perspective.

The key is clear communication about each group's purpose. Members can join whichever spaces meet their needs, but they must respect each group's focus. This structure allows each community to centre its specific needs while acknowledging the deep connection between them. Many households have members in both groups.

Moderating Mixed-Outcome Spaces

If your co-survivor space welcomes people regardless of whether the patient survived, you are moderating one of the most emotionally complex environments in peer support. This requires specific skills and awareness.

The central tension: In any given thread, you may have someone celebrating their partner's recovery alongside someone whose partner died during the same type of event. Both experiences are valid. Both people deserve support. But the juxtaposition can be excruciating for the bereaved member—and potentially guilt-inducing for the one whose person survived.

Practical approaches:

- **Set expectations clearly at joining.** Your welcome message should acknowledge that the group includes people with different outcomes, and that members will encounter both celebration and grief. This is not to discourage anyone, but to prepare them.
- **Create space for outcome-specific conversations.** Consider periodic posts specifically inviting bereaved co-survivors to share, or threads where only those whose person survived respond. This prevents bereaved members feeling invisible in a sea of recovery stories.
- **Watch for unintentional insensitivity.** A post saying "So grateful my husband survived—I can't imagine what I'd do without him" is completely understandable, but can

land painfully on someone who lost their husband last month. You cannot prevent all such moments, but you can gently redirect if needed.

- **Know when grief is dominating.** If your co-survivor space becomes predominantly about loss rather than processing the resuscitation experience, it may be drifting from its purpose. Gently redirect ongoing grief discussions to bereavement specialists while affirming that the person belongs in your space for resuscitation-related support.
- **Recognise different timelines.** Someone whose person died last week is in a different place than someone processing CPR they performed five years ago. Both are valid, but their needs differ.
- **Have clear escalation paths.** Know which local bereavement services you trust, and be ready to make warm referrals when someone needs more than your space can provide.

What bereaved co-survivors often need from your space:

- Validation that they did everything they could
- Answers to questions only others who have been there can address (Was my person in pain? Did I hurt them doing CPR? Should I have done something differently?)
- Connection with others who understand the specific trauma of witnessing a resuscitation
- Permission to feel whatever they feel—including anger, guilt, or relief

What they typically need from elsewhere:

- Ongoing grief counselling
- Support through anniversaries, holidays, and long-term adjustment
- Help with practical matters (inquests, estates, explaining to children)
- Community with others who have lost loved ones

The goal is not to exclude bereaved co-survivors but to be honest about what you can and cannot offer—and to ensure they get appropriate support for all their needs, not just the ones you can address.

Signposting to Specialist Support

No single organisation can address every need. Part of serving your community well is knowing when to point people elsewhere—and being clear about the boundaries of what you offer.

A critical distinction: resuscitation trauma versus bereavement support. If your network, like ours, welcomes co-survivors who witnessed a resuscitation where the patient did not survive, you must be clear about what you are offering. You can help people process the traumatic experience of the resuscitation itself—the CPR, the waiting, the questions about whether they did enough. This is valuable and needed. But ongoing bereavement support—grief counselling, processing the loss of a loved one over months and years—is specialist work that requires different skills and resources. A peer support network founded by and for survivors is not equipped to provide this, and attempting to do so risks serving neither population well.

Be explicit about this boundary, both in your group descriptions and when welcoming new members. Something like: "We support anyone affected by a resuscitation event, regardless of outcome. If the person you tried to save did not survive, we can help you process that traumatic experience and connect with others who understand. For ongoing bereavement support, we recommend [local bereavement organisations]." This is not rejection—it is responsible signposting to organisations better placed to help.

Build relationships with specialist organisations and actively signpost members who need more targeted support. Common referral categories include:

- **Bereavement support** (for ongoing grief following sudden cardiac death—specialist bereavement charities are better equipped for this than peer support networks)
- **Acquired brain injury support**
- **Post-intensive care syndrome (PICS) and delirium support**
- **Mental health support** (anxiety, depression, PTSD are common after cardiac arrest)
- **ICD (implantable cardioverter-defibrillator) support** (adjustment to living with a device, shock anxiety, lifestyle concerns)
- **Professional counselling services**

In your country, identify the equivalent organisations. Most nations have bereavement charities, brain injury associations, mental health services, and patient organisations for specific cardiac conditions. Your national resuscitation council may be able to help you identify appropriate referral pathways. Public mental health services are often under pressure with lengthy waiting times, so having alternative pathways to professional support can make a real difference for people in crisis.

A note on ICDs: Many cardiac arrest survivors are fitted with an ICD, and this brings its own set of concerns—body image, fear of shocks, lifestyle restrictions, device replacements, and the psychological weight of carrying a machine that might save your life at any moment. Over time, we have developed substantial resources on ICD-related topics, drawing on our members' collective experience. If your community includes ICD recipients, this will become one of your most frequently discussed areas.

Build your own list of trusted organisations in your country. When someone's needs exceed what peer support can provide—or when they need specialist expertise you lack—a warm referral to the right organisation is more valuable than trying to be everything yourself.

Partner support: Established organisations can help a new network in practical ways beyond signposting—funding leaflets, covering venue costs, providing access to services. Look for organisations whose mission aligns with yours and approach them about collaboration. These partnerships can be transformative for a growing network.

Making the Case to Healthcare Partners

When you approach healthcare systems for referrals, the co-survivor model is a strength. Clinicians increasingly recognise family impact but often have no resources to address it. A peer network that welcomes both patients and families fills a genuine gap.

In 2025, the term "co-survivor" was included in the European Resuscitation Council guidelines for the first time—a recognition that this population matters and deserves support. You can reference this when making the case to clinicians in your country.

Phase 2: Building the Fire (Years 2–3)

By now, your fire is established. It no longer threatens to go out if you look away for a moment. But it still needs fuel and attention to grow. This is the phase where you add larger logs, build structure around the flames, and create something that can sustain itself through difficult weather.

A warning about the transition ahead: The period between roughly 50 and 500 members is often the hardest. Your group is too large to feel intimate but too small to have developed the self-sustaining culture of a mature community. Moderation demands spike. Problem members appear. The emotional labour per person is at its peak. If you are going to burn out, this is when it will happen. Recognise this phase for what it is—a necessary but temporary transition—and be deliberate about protecting yourself and your team through it.

When to Add Structure

There comes a point when informal arrangements are no longer enough. Signs you need more structure:

- Moderation is overwhelming your small team
- Members are asking for things you cannot provide (regional meetups, resources, representation)
- Healthcare organisations want to partner but need a "proper" organisation to work with
- You are spending money and need transparency about finances
- Other people want to help but you have no way to organise them

Do not add structure prematurely. Every layer of formality adds administration. Wait until the pain of informality exceeds the cost of bureaucracy.

Scaling Your Welcome Process

In the early days, you might write a personalised introduction post for every new member. This is wonderful—nothing says "you matter" like individual attention. But it does not scale.

As you grow, you will need to move to a template welcome message. This feels like a loss, but it can actually be better for members if done well:

- **Consistent information:** Every new member gets the same essential starting points—where to find help, how to introduce themselves, key guidelines.
- **Faster response:** A template sent promptly beats a personalised message sent three days later.
- **Sustainable for moderators:** Your volunteers can actually maintain this without burning out.

Design your template carefully. It should feel warm, provide genuinely useful orientation, and invite the new member to take a next step (introduce yourself, read this resource, ask a question). Test it on new members and refine based on feedback.

Regional Meetups: Online to In-Person

Online community builds breadth. In-person meetups build depth. Both matter.

When members meet face-to-face, something shifts. They see that other survivors exist—not just as names on a screen, but as real people living real lives. The abstract becomes concrete. There is something irreplaceable about being in a room with people who understand—the conversations that happen over coffee, the connections that form naturally, the sense of not being alone that no online interaction quite matches.

Our journey: We have held over fifty in-person events since that first pub meeting in February 2015, when thirteen of us gathered in London. Growth was not linear. We held successive meetups in London and other large cities, gradually increasing attendance. By 2017, a London meetup drew over forty people and we needed to hire a room—that is when SADS UK stepped in to help fund the deposit. In June 2018, with support from the Essex Cardiothoracic Centre, we attempted a Guinness World Record for the largest gathering of cardiac arrest survivors. Over two hundred people came; 127 verified survivors set the record. It was an outstanding success. In 2019, we moved to a hotel in Rutland for "Not Alone," our first proper national conference, with around 140–150 attendees. Then the pandemic halted everything for several years. In November 2023, "Survive and Thrive" in Daventry brought nearly two hundred people together again. In May 2025, "10 Years Together" celebrated our anniversary with around two hundred attendees including a healthcare professional track.

The feedback from every event has been outstanding. People leave changed. But here is the honest truth: these events require enormous energy and resources. Planning a national conference can consume months of volunteer time. The logistics—venues, catering, registration, accessibility, speakers, travel, accommodation—are substantial. And while you are organising a conference, you are not running the day-to-day community. The work does not stop; it just piles up. Regional meetups are lighter-lift but still require someone to step up and organise each one, which happens sporadically depending on who has capacity.

We think in-person events are absolutely worth doing. The connections formed, the hope kindled, the relationships with healthcare professionals deepened—these cannot be replicated online. But go in with eyes open about the true costs, which are not only financial.

Starting regional meetups:

- **Begin with one:** Do not try to launch everywhere at once. Start in one location where you have an enthusiastic local volunteer.
- **Keep it simple:** A pub, a coffee shop, a community centre. No agenda required. The conversation happens naturally.

- **Timing matters:** Daytime works for retired members; evenings for working-age survivors; weekends often work best for larger events where people may be travelling. Consider rotating to accommodate different schedules.
- **Promote consistently:** The first meetup may have three people. The fifth may have fifteen. Keep going.
- **Document and share:** Photos (with permission) and brief reports help other regions see what is possible.

Safety at in-person events: It is worth knowing where the nearest AED is at your venue, though the likelihood of needing it is very low. Your members will likely appreciate knowing someone has thought about it.

Protecting the space: We advertise regional meetups only within our private groups, not publicly. This ensures we reach the right people—those with lived experience who need peer support—while avoiding uninvited attention from journalists, researchers seeking subjects, or others who might have different agendas. Smaller meetups are more vulnerable to disruption; a stranger with a notebook changes the dynamic entirely. For larger national conferences, public promotion is appropriate—there is safety in numbers, and the format is different. But for intimate regional gatherings where people share vulnerably, keep the invitation within your community.

Group dynamics: Be mindful of who attends smaller meetups. A gathering dominated by one family group—say, a survivor with multiple relatives—can inadvertently make other attendees feel like outsiders in what should be a shared space. Aim for a mix that allows everyone to connect as equals. If someone wants to bring several family members, consider whether the meetup is large enough to absorb them without changing the character of the group.

Venue costs: In the early days, a few tables in a pub corner cost nothing. As you grow, you may need private spaces—and these often come with hire fees or minimum spend requirements. This can become prohibitively expensive. Partnerships with established charities can help bridge these practical gaps—our partner organisation helped fund our venue deposits when we faced this challenge.

Healthcare professionals at events: Our larger conferences now include dedicated sessions for clinicians. This benefits everyone—healthcare professionals learn from survivors in ways that research papers cannot convey, and survivors gain access to expertise in a more relaxed setting. The relationships formed often continue long after the event, creating referral pathways and collaboration opportunities. Many clinicians tell us they find these events as valuable as we do.

Supporting regional leaders:

As meetups multiply, you need local volunteers to organise them. Look for members who:

- Are reliably present and engaged
- Have processed their own experience enough to support others
- Show natural warmth and organisational ability

- Can commit to ongoing involvement

Give them autonomy with support. Provide guidelines and resources, but let each region develop its own character.

Healthcare Partnerships Without Dependence

Relationships with healthcare systems are valuable but complicated. You want referrals without becoming captured.

Research consistently shows that immediate hospital care for cardiac arrest is often excellent, but follow-up care is a postcode lottery—inconsistent, underfunded, and frequently absent altogether. This is particularly true for survivors with no identified cause, who may be excluded from rehabilitation services entirely. Your peer support network exists partly because this gap exists. Partnering with healthcare does not mean pretending the gap is not there.

The evidence for peer support: When approaching healthcare partners, it helps to know that peer support has a growing evidence base. Research across health conditions shows reductions in isolation and improved mental health outcomes, with some studies reporting reduced emergency department visits and hospital readmissions. For cardiac conditions specifically, peer support provides understanding of diagnosis from those with lived experience, practical guidance on recovery, emotional support during anxiety, and connection to others navigating similar challenges. Peer support complements rather than replaces professional care—a point worth emphasising to clinicians who may be uncertain about its role.

What healthcare partners can offer:

- Referral pathways (cardiac rehabilitation mentioning your group to patients)
- Credibility (being recommended by clinicians matters to many patients)
- Access (hospital spaces for meetings, inclusion in patient information packs)
- Collaboration on research and guidelines

What to protect:

- **Independence:** You must be able to advocate for patients even when it is uncomfortable for healthcare systems.
- **Authentic voice:** Clinical approval processes can sanitise the raw honesty that makes peer support work.
- **Member trust:** If members feel the group is just an extension of the hospital, they will not speak freely.

Practical approach: Cultivate individual relationships with sympathetic clinicians rather than seeking formal institutional partnerships initially. One cardiac rehabilitation nurse who mentions your group to every patient is worth more than an official memorandum of understanding that never gets implemented.

When you do formalise relationships, be clear about roles. You are not an extension of healthcare services. You are a patient-led community that healthcare services can refer to.

A model worth noting: In Sweden, all CPR instructors receive information about the Swedish Network for Cardiac Arrest Survivors and Relatives to distribute to survivors before hospital discharge. This creates a structured referral pathway that most peer support organisations lack. If you can establish similar arrangements—information packs given to patients at discharge, posters in cardiac rehabilitation waiting rooms, or inclusion in hospital patient information systems—you create visibility at the moment when survivors most need to know support exists.

Navigating more regulated environments: This guide reflects the UK context, where informal peer support networks can operate relatively freely. In some countries—particularly those with more centralised or regulated healthcare systems—the landscape is different. You may face:

- Data protection requirements that make patient referrals complicated
- Liability concerns that make hospitals cautious about recommending informal groups
- Formal accreditation requirements for patient support organisations
- Cultural expectations that support comes through official channels

If you are working in such an environment, you may need to engage more explicitly with institutional processes than we have described here. This might mean seeking formal recognition, partnering with established patient organisations, or working within hospital structures rather than alongside them. The core principles—survivor voice, peer connection, independence of perspective—remain important, but the implementation may require more compromise and navigation than the informal model we have used. Do not assume that what worked in one country will translate directly to another.

Volunteer Recruitment and Management

As you grow, you need more people. Moderators are volunteers too, but you will also need help with other roles: organising meetups, managing social media, writing content, coordinating events. Volunteer management is its own skill.

The virtuous cycle: One of the most rewarding aspects of peer support is watching members progress from needing help to offering it. Someone who arrived terrified and overwhelmed gradually finds their footing, starts responding to others' posts, and eventually volunteers to help run the community. Today's newly supported become tomorrow's peer supporters. This cycle is the engine of sustainable peer support—and one of the clearest signs that your network is working.

Finding volunteers: The best volunteers are usually members who have been quietly contributing for months. They understand the culture because they have lived it. Approach people who demonstrate:

- Consistent, thoughtful engagement
- Emotional stability and resilience

- Reliability (they show up when they say they will)
- Alignment with your values

Setting expectations: Be honest about what you need and what you can offer (usually nothing but gratitude). Specific roles work better than general "helping"—people like to know what they are responsible for.

Supporting volunteers: Remember that your volunteers are also survivors or co-survivors. Their capacity will vary. Build in flexibility, recognise their contribution, and give them permission to step back when needed.

Building Your Moderator Team

Moderators deserve their own section because the role carries particular weight. They are the face of your community, making daily decisions that shape member experience. Some principles we have learned:

Selection criteria:

- Must be a member of the group for a reasonable period (we require six months minimum)
- Survivors and co-survivors should be at least one year post-event—moderating requires emotional stability that recent trauma rarely allows
- Must be able to commit regular time to the role
- Should demonstrate the values you want the community to embody

Probation and support: New moderators need time to learn. We use a three-month probationary period with active support from experienced moderators or trustees. Do not throw people in at the deep end.

Regular check-ins: Meet with your moderator team regularly—at least quarterly, more often if needed. This is not just administrative; moderators absorb difficult content constantly and need space to process it together. The same principle applies to other volunteers, though moderators typically need more support given what they encounter.

Clear escalation paths: Moderators need to know when to handle something themselves and when to escalate. Define what decisions they can make independently and what requires consultation.

Annual review: Check in formally each year. Is each moderator still happy in the role? Still meeting the criteria? Still have capacity? People's circumstances change, and the role should never feel like a trap.

Volunteers, not employees: Moderators give their time freely. They receive no payment and should never be treated as staff. Respect their boundaries and their lives outside the group.

Consider documenting your moderator policies formally as you grow. This protects everyone—moderators know what is expected, and the organisation has clear processes if problems arise.

Power and humility: Peer support leadership carries informal power, whether you want it to or not. Long-standing moderators become authority figures. Vulnerable members may defer to them excessively. Boundaries can blur subtly over years. The antidote is not to deny that this power exists—it is to acknowledge it openly and guard against its misuse. Transparency about decisions, shared leadership where possible, and genuine humility about your own limitations all help. If you find yourself thinking "I know what's best for these people," that is usually a sign to step back and listen more.

When a Moderator Is No Longer a Fit

Finding moderators is hard. Letting them go is harder. But it is sometimes necessary, and avoiding the conversation causes more damage than having it.

Warning signs:

- Inconsistent presence or reliability
- Tone that has become harsh, dismissive, or overbearing
- Boundary issues with members (becoming too involved, or too distant)
- Personal circumstances affecting their capacity
- Values drift—no longer aligned with how the community operates
- Conflict with other moderators that cannot be resolved

Why this matters: In peer support communities, a moderator who has become toxic or overbearing can do significant harm. Members are vulnerable. They come seeking support, not judgement. A moderator who has lost perspective—perhaps because their own recovery has stalled, or because the role has become about power rather than service—can drive people away or cause real distress.

How to approach it:

- Start with a private conversation. Assume good intent initially—they may not realise how they are coming across.
- Be specific about what you have observed and why it concerns you.
- Listen to their perspective. There may be personal circumstances you are unaware of.
- Offer alternatives: a break, a reduced role, stepping back to regular membership.
- If the behaviour continues, be clear that the role is no longer working and needs to end.
- Thank them genuinely for their contribution. Most moderators who become problematic started out as valuable volunteers.

Protecting the community: Your primary responsibility is to the members, not to individual moderators' feelings. A difficult conversation with one person is better than ongoing harm to many. Document your concerns, follow your policies, and act when needed.

This is one of the hardest parts of running a peer support network. No one talks about it, but everyone who has done this work for long enough has faced it.

Moderator Wellbeing and Secondary Trauma

Moderators absorb difficult content constantly. They read about fear, grief, medical complications, relationship breakdown, and occasionally crisis and self-harm. This takes a toll, even when moderators are not consciously aware of it.

Recognise the cumulative weight: A single distressing post is manageable. Hundreds over months and years are not. Moderators may not notice the gradual impact until they find themselves irritable, emotionally flat, or dreading opening the group.

Build in debriefing: After any crisis post or particularly difficult content, create space for moderators to talk it through—with you, with each other, or with someone outside the group. This should not be optional. Processing difficult content is part of the role, not an admission of weakness.

Rotate exposure to difficult content: If your platform allows, consider having moderators take turns monitoring for crisis posts or handling membership requests from bereaved applicants. No one person should carry all the heavy material.

Normalise stepping back: Moderators need to know they can take breaks without losing their role. A week away from moderating is not failure—it is maintenance. Build cover into your team structure so breaks are genuinely possible.

Watch for warning signs: Changes in tone, reduced engagement, cynicism about members, or reluctance to log in may indicate a moderator needs support. Check in before problems escalate.

Your own wellbeing matters too: If you are the founder, you have probably been absorbing this content longer than anyone. Everything in this section applies to you as well.

Collating Community Knowledge

One of the most valuable things you can do is pay attention to what your community knows. Over time, the same questions come up repeatedly: Can I drive? What about travel insurance? Will I ever feel normal again? Your members, collectively, have answered these questions hundreds of times.

Start capturing this knowledge. It does not need to be formal—just begin collecting the useful information and tips that emerge from your community discussions. Save the particularly helpful posts. Note the resources members recommend to each other. Document the practical wisdom that experienced survivors share with newly diagnosed members.

Identifying the gaps: Pay attention to questions that arise repeatedly—these reveal where survivors struggle to find reliable information. For us, certain themes emerged consistently:

driving regulations and licensing authority requirements, travel insurance difficulties, life insurance exclusions, returning to work, managing fatigue, and navigating the emotional journey toward a "new normal." These recurring questions showed us where the gaps were—and where we could make a difference by creating clear, reliable resources.

This process can grow organically. For us, it started as a simple collection of frequently asked questions and evolved into our website. From there, we developed a library of resources:

- **Website pages** covering common topics (driving regulations, travel considerations, returning to work, emotional recovery)
- **Leaflets and publications** that can be downloaded, printed, or shared—our leaflet on fatigue has been particularly valuable
- **Blog articles** written by members sharing their personal experiences and insights

Eventually, we compiled the best of these member-written articles into two books: *Life After Cardiac Arrest Volume 1* and *Volume 2*. These are not clinical texts—they are the authentic voices of survivors and co-survivors sharing what they have learned. That authenticity is what makes them valuable. All of our publications are available at scauk.org/pubs

Several of our publications have been translated into other languages by survivor groups in other countries. We are happy to share our resources with anyone establishing similar networks—there is no need to start from scratch when materials already exist that can be adapted to your context.

You do not need to start with books. Start with a shared document or a pinned post collecting your community's best advice. The important thing is recognising that your members' collective experience is a resource worth preserving and sharing. New members should not have to wait for someone to happen to answer their question—the community's accumulated wisdom should be accessible from day one.

Building External Channels

As your community matures, consider expanding beyond your core platform. Different channels serve different purposes and reach different audiences:

Podcasts: Audio content allows survivors and co-survivors to share their stories in depth. It reaches people who prefer listening to reading, and can be consumed during commutes or rehabilitation exercises. Our *Life After Cardiac Arrest* podcast features conversations with survivors, co-survivors, clinicians, researchers, and innovators—over sixty episodes and growing.

YouTube: Video content can demonstrate what words cannot—the reality of life after cardiac arrest, the faces behind the statistics, the possibility of recovery. It also helps with search visibility; many people turn to YouTube when researching health conditions.

Other social media: X (formerly Twitter) was once where "MedTwitter" lived—a vibrant community of medical professionals discussing research and clinical practice. Due to recent changes in ownership, many have migrated to other platforms, notably BlueSky. If connecting with healthcare professionals is a priority, it is worth establishing a presence on whichever platforms they are currently using, but be aware this landscape shifts.

Managing multiple channels: If you do expand to multiple platforms, consider using scheduling tools that allow you to post to several channels simultaneously. Services like Buffer, Hootsuite, or Social Champ can save significant time, though they come with subscription costs. Weigh this against the time you would spend posting manually to each platform.

The key is not to spread yourself too thin. Each channel requires time and consistency to maintain. Start with one, establish it properly, then consider expanding. And always remember that these external channels support your core community—they are not replacements for it.

Phase 3: A Fire That Sustains Itself (Years 4+)

A mature fire is different from a new one. It has a bed of coals that holds heat even when flames die down. It can survive rain and wind. Others can gather around it without your constant attention. But it still needs someone watching, still needs fuel, still needs care—just differently than before.

Formalising (Or Not)

At some point, you will face pressure to become a "proper" organisation. This usually means registering as a charity, establishing a board, creating governance documents, and all the administrative apparatus that entails.

Benefits of formalisation:

- Legal protection for founders and volunteers (personal liability is limited)
- Ability to receive grants and donations with tax benefits for donors
- Increased credibility with healthcare partners, funders, and media
- Clear governance when decisions are contested
- Succession planning—the organisation can outlive its founder
- Access to charity infrastructure (banking, insurance, official recognition)

Costs of formalisation:

- Administrative burden (annual reports, accounts, regulatory compliance, trustee meetings)
- Finding and retaining trustees (people willing to take on legal responsibility for free are not abundant)
- Board dynamics (managing disagreements, ensuring trustees actually engage, avoiding rubber-stamping)
- Mission drift risk (boards sometimes want to "professionalise" in ways that lose authentic voice)
- Slower decision-making (you cannot just act; you need approval)
- Public scrutiny (charity accounts and reports are publicly available)
- The work of compliance never ends—it is not a one-time setup

The honest reality: Becoming a charity made SCA UK more sustainable and credible, but it also made it slower and more complicated. Every decision now involves more people. Every expenditure must be justified. The spontaneity of the early days is harder to recapture. Whether this trade-off is worth it depends on your ambitions and circumstances.

There is no right answer. Some excellent peer support networks remain informal. Others become charities. Consider what you actually need—do not formalise just because it seems like the grown-up thing to do.

Beyond the binary: "Charity or not" is not your only choice. Depending on your jurisdiction, intermediate options may exist—Community Interest Companies (CICs) in the UK, associations in many European countries, fiscal sponsorship arrangements where an established charity acts as your legal umbrella. These can provide some benefits of formalisation (credibility, limited liability, ability to receive grants) without the full administrative burden of independent charity status. Research what structures exist in your country before assuming you must choose between informal group and registered charity.

If you do formalise, protect the things that make you effective. Ensure your governance documents preserve survivor leadership and authentic voice as non-negotiable principles.

Leadership Beyond the Founder: The Bus Factor

No organisation should depend entirely on one person. This is easy to say and hard to implement.

The "bus factor" is a blunt way of asking: what happens if the founder gets hit by a bus tomorrow? For cardiac arrest survivor networks, this question has particular weight—we know better than most that life can change in an instant. If your network would collapse without you, that is a vulnerability you need to address.

Start early:

- Document what you do (not just what the organisation does, but literally what you personally do—the passwords, the processes, the relationships, the institutional knowledge that lives only in your head)
- Delegate genuinely (not just tasks, but authority and decision-making)
- Develop others' capabilities (let people make mistakes and learn)
- Make yourself progressively less essential
- Identify potential successors and invest in their development
- Ensure more than one person has access to critical accounts and systems

Succession is not retirement: You do not need to be planning to leave to plan for succession. It is about resilience. If you are ill for three months, can the network continue? If you burn out and need to step back, is there someone ready to step up?

The "Bus Folder": Create a secure document or folder that a trusted deputy can access in an emergency. Include:

- Login credentials for all platforms (ideally in a password manager with shared access)
- Bank account details and mandate information

- Domain name and website hosting credentials
- List of key contacts (healthcare partners, trustees, regular volunteers)
- Overview of recurring tasks and when they need doing
- Any contracts or agreements in force
- Instructions for accessing email and social media accounts

Make it accessible in an emergency: A Bus Folder is useless if no one can find it when needed. Use a password manager that supports emergency access (most major services like 1Password, Bitwarden, or LastPass allow you to designate trusted contacts who can request access after a waiting period). Alternatively, store credentials in a secure shared location that at least one other trustee can access. A physical folder in a drawer or a Google Doc that only you can access defeats the purpose. Test the access—make sure your deputy can actually get in before they need to.

Store this securely and tell at least one other person where it is. Update it regularly. The bus factor needs a bus folder.

This requires ego management. The network you built is not your property. If it depends entirely on you, you have built something fragile—and you have also trapped yourself.

Research Partnerships and Credibility

As your network matures, researchers may approach you. This can be valuable—for them, for you, and for the broader understanding of cardiac arrest survivorship.

Why this matters: Healthcare systems are not yet developed enough to meet the full needs of survivors and co-survivors. Much of what we know about post-arrest recovery comes from research—and that research is increasingly expected to involve patients and the public as partners, not just subjects. The principle is simple: research should be carried out "with" or "by" people with lived experience, rather than "to", "about", or "for" them. A peer support network provides exactly the community that makes this possible. You become a bridge between researchers asking questions and survivors living the answers.

What you can offer researchers:

- Access to participants (surveys, interviews, focus groups)
- Patient and public involvement in study design
- Real-world insight into survivor priorities
- Dissemination of findings to the community

What to insist on:

- Genuine partnership (not just access to your members)
- Patient involvement from the start, not as an afterthought
- Clear communication about how findings will be shared

- Protection of member privacy and data
- Recognition of the network's contribution

Be selective. Not every research request deserves your members' time and energy. Prioritise studies that address questions survivors actually care about.

Funding Realities

Money is not essential to start, but it helps to grow. However, funding comes with complications that are worth understanding before you pursue it.

Sources:

- Member donations (small but reliable, and reinforces community ownership)
- Fundraising events (time-intensive, but can also build community)
- Grant applications (competitive, often restricted to specific activities, and require significant time to write—a successful application may take weeks of work, and most applications are unsuccessful)
- Healthcare system contracts (can provide stability but almost certainly will compromise independence if the contract is substantial—you may find yourself shaping your work around funder priorities rather than member needs)
- Corporate sponsorship (can provide unrestricted funds but carries reputational risks—consider carefully whether the association aligns with your values)

Principles:

- Start lean and stay lean. Overhead kills small organisations.
- Do not chase funding that would distort your mission. The time spent pursuing and managing grants is time not spent on your community.
- Diversify—dependence on a single funder is dangerous. If that funding disappears, so might your organisation.
- Be transparent with members about money.
- Never compromise on free access. If funding requires you to charge members, it is the wrong funding.

What budgets actually look like:

Zero budget (entirely possible): Facebook group (free), Google Workspace for documents and forms (free), Canva for graphics (free), Mailchimp for up to 500 email contacts (free), Zoom for short meetings (free), volunteer time (unpaid). Many peer support networks operate this way indefinitely.

Low budget ($500–1,500/year): Everything above, plus: domain name and basic website hosting ($50–150/year), Zoom Pro for longer meetings ($120–180/year), Mailchimp paid tier for larger lists ($100–300/year), event costs like refreshments or small venue hire (variable), printed materials ($100–200/year), charity registration and compliance costs if formalised (variable).

What creates overhead pressure: Paid staff (even part-time), office space, insurance beyond basic requirements, professional services (accountants, lawyers), ambitious events with venue hire and catering. Once you commit to recurring costs that require funding to sustain, you are on a treadmill. Be very cautious about stepping onto it.

Many peer support networks operate effectively with minimal budgets. Do not assume you need significant funding to be valuable. The most important resources you offer—lived experience, understanding, presence—cost nothing.

The Invisible Curriculum

This chapter covers what no one tells you about running a peer support network.

What You Will Actually Spend Your Time On

It is not what you expect.

- **Reading:** Every post, every comment, every membership request. You need to know what is happening in your community.
- **Responding:** Not just moderating, but genuinely engaging. Your presence sets the tone.
- **Mediating:** Disagreements between members. Hurt feelings. Misunderstandings.
- **Worrying:** About the member who posted something concerning at 2am. About the angry email from someone who felt dismissed. About whether you are doing enough.
- **Administration:** Emails, messages, volunteer coordination, event planning, partnership discussions. The unglamorous work that keeps everything functioning.

The visible part—the thriving community, the supportive responses, the grateful testimonials—is the tip of an iceberg of invisible labour.

Common Pitfalls

Trying to scale before you are ready: Growth for its own sake is not the goal. A community of 200 genuinely engaged members is worth more than 2,000 inactive ones. Grow at the pace your infrastructure can support.

Losing authentic voice: As organisations mature, they often become more "professional"—more careful, more polished, more bland. Resist this. The raw honesty of lived experience is your greatest asset.

Founder burnout: The work is emotionally demanding. You are constantly absorbing other people's pain. If you do not protect your own wellbeing, you will burn out. This is not a failure of dedication; it is inevitable physiology.

Mission creep: People will ask you to do things beyond your scope. Campaign on this issue. Provide this service. Address this related condition. Sometimes you should expand; often you should not. Stay focused on what you do well.

Dependency dynamics: Some members may become over-reliant on the community or on you personally. Given how much peer support can mean to people, this is not surprising—but it is not healthy for anyone. Peer support supplements other relationships and professional help; it does not replace them.

When Members Need More Than Peer Support

Peer support is not therapy. It is not crisis intervention. It is not professional mental health care. You need to recognise when someone needs help you cannot provide.

Warning signs:

- Expressions of suicidal thoughts or self-harm
- Severe depression or anxiety that is not improving
- Psychotic symptoms or detachment from reality
- Escalating crisis despite community support

Your role: You are not responsible for diagnosing or treating anyone. You are responsible for:

- Creating a supportive environment
- Recognising when that environment is not enough
- Gently encouraging professional help
- Knowing what resources exist in your country
- Having a plan for crisis situations

Develop relationships with mental health professionals who understand cardiac arrest. Having someone you can consult (not refer members to, but consult yourself) is valuable.

Looking After Yourself

Running a peer support network means absorbing other people's pain, day after day, often invisibly. If you do not actively protect your own wellbeing, you will burn out. This is not a failure of dedication—it is inevitable physiology.

- **Set boundaries:** You do not have to respond to every message immediately. You do not have to be available 24/7. You are allowed to take holidays.
- **Share the load:** If you are the only person carrying emotional weight, fix that. Develop a team.
- **Maintain perspective:** The community matters, but so does your health, your relationships, your life outside this work.
- **Get support:** Talk to someone—a partner, a friend, a therapist—about the difficult parts. Do not process everything alone.
- **Know when to step back:** If running the network is damaging your own wellbeing, that is a sign something needs to change.

The best thing you can do for your community is remain healthy enough to lead it.

Advanced Moderation Challenges

As your community matures, you will encounter situations that basic guidelines do not cover. This chapter addresses the complex moderation challenges that typically emerge in year two and beyond—situations where judgment matters more than rules.

Members with Cognitive Impairment

Cardiac arrest frequently causes hypoxic brain injury. Some survivors recover fully; others live with permanent cognitive changes ranging from subtle to profound. Your community will include both—and moderating this requires sensitivity.

Common presentations:

- Repetitive posting (asking the same question multiple times, not remembering previous answers)
- Difficulty following conversation threads or group norms
- Communication that seems confused, tangential, or inappropriate
- Memory gaps that affect their ability to participate coherently
- Frustration or emotional dysregulation when they struggle to express themselves

Moderation approaches:

- **Patience is paramount.** A member posting the same question weekly is not trying to annoy anyone—they may genuinely not remember asking before. Respond kindly each time, or gently point them to a pinned resource.
- **Private guidance over public correction.** If a member's posts are confusing others, reach out privately rather than correcting them publicly. They may be embarrassed by their difficulties.
- **Distinguish impairment from disruption.** A member whose cognitive impairment leads to repetitive or confused posting is different from a member being deliberately difficult. Moderate accordingly.
- **Support the carers too.** Partners of survivors with significant cognitive deficits often join co-survivor spaces. Their experience is distinct—ongoing caregiving, grief for the person their loved one used to be, exhaustion, isolation. Acknowledge this population explicitly.
- **Manage community expectations.** Some members may become frustrated with repetitive posts or confusing interactions. Remind your community gently that brain injury is common after cardiac arrest and that patience is part of supporting each other.
- **Know your limits.** Severe cognitive impairment may mean peer support is not the right intervention. If a member cannot meaningfully participate—or if their participation is consistently distressing to themselves or others—it may be kindest to speak privately with their carer about whether this space is serving them.

Avoid the implicit "recovery arc." Much peer support language assumes improvement over time. For survivors with permanent cognitive deficits, this narrative does not fit. Be mindful of framing that implies everyone will "get better"—some members are managing a permanent new reality, and they need to feel that reality is acknowledged and valid.

Medical Disagreements and Misinformation

Your rule says "no medical advice." In practice, the boundary is messier.

Common challenges:

- **Contextually dangerous accuracy.** "I stopped taking my beta blockers and feel great" may be true for that person, but could encourage others to make dangerous decisions. Similarly, "My doctor said I don't need an ICD" may be accurate but could undermine others' trust in their own treatment plans.
- **Alternative and complementary therapies.** Members may advocate for supplements, diets, or treatments that range from harmless to potentially dangerous. Where do you draw the line?
- **Distrust of medicine.** Some survivors develop profound distrust of healthcare systems, sometimes for understandable reasons. When they encourage others to share that distrust, it can become harmful.
- **Disagreements between members.** Two members may have received different advice from their cardiologists and argue about whose approach is correct.

Practical approaches:

- **Distinguish experience-sharing from recommending.** "This worked for me" is different from "You should do this." The former is peer support; the latter crosses into advice. Encourage the former framing.
- **Add context rather than removing content.** Rather than deleting a post about stopping medication, consider adding a moderator note: "Everyone's situation is different—please discuss any medication changes with your own medical team."
- **Be consistent about boundaries.** If you allow discussion of mainstream supplements, you will struggle to prohibit discussion of alternative therapies. Decide where your line is and apply it consistently.
- **Redirect to professionals.** For genuinely medical questions, your standard response should be: "That's really a question for your medical team, who know your specific situation."
- **Tolerate some messiness.** Peer support groups are not clinical spaces. Members will share opinions you disagree with, recommend things you would not recommend, and occasionally say things that make you wince. Moderate genuine harm, but accept that you cannot—and should not—control all medical discussion.

Recurrence and ICD Events

Some survivors have multiple cardiac arrests. Some experience ICD shocks—which are traumatic events in themselves. The implicit narrative of "survival and recovery" does not capture this reality.

Recurrent cardiac arrest:

- Members who have survived two, three, or more arrests carry a different psychological burden. They know viscerally that it can happen again.
- Their presence can be frightening for newer members still hoping their arrest was a one-time event. Acknowledge this tension.
- They may need space to express fear, anger, or exhaustion that feels different from first-time survivors' experiences.

ICD shocks:

- An ICD shock—even an appropriate one—is deeply traumatic. The device that is supposed to protect you has just delivered a powerful electric shock to your heart.
- Inappropriate shocks (when the device fires unnecessarily) are even more psychologically damaging, eroding trust in the device meant to save your life.
- Members may develop shock anxiety, fear of activity, or reluctance to leave home.
- Some members face decisions about ICD replacement, lead extraction, or device deactivation—each carrying significant emotional weight.

How to support:

- Validate that recurrence and shocks are genuinely difficult, not something to minimise or move past quickly.
- Connect members who have experienced similar events—peer support from someone who has been shocked and found ways to manage the anxiety is invaluable.
- Recognise that these experiences can retraumatise members, returning them to the acute phase of recovery even years after their original arrest.
- Know when professional psychological support is needed—shock anxiety and recurrence-related PTSD may require more than peer support can provide.

Cultural, Religious, and Linguistic Considerations

Cardiac arrest affects people of every background. Your moderation must accommodate this diversity.

Religious interpretations of survival:

- Many survivors attribute their survival to divine intervention: "God saved me for a purpose," "It was not my time." This framing brings genuine comfort.
- Other members may find such framing alienating or even distressing—implying that those who died were not saved for a reason.
- Moderate with light touch. Allow members their own meaning-making while preventing any framing that implies judgment of others' outcomes.

Cultural differences in discussing health:

- In some cultures, discussing personal health publicly carries stigma. Members from these backgrounds may participate less visibly or prefer private support.
- Family roles in caregiving vary culturally. Assumptions about who provides care, who makes decisions, and how illness is discussed within families differ across cultures.
- Be aware of these differences without stereotyping. Create space for different approaches without requiring everyone to share publicly.

Language considerations:

- Even in a single-country group, not all members will share the same first language. Medical terminology is particularly challenging for non-native speakers.
- Write important resources in clear, simple language.
- Be patient with members whose posts may be harder to understand due to language barriers.
- Consider whether translated resources or multilingual moderators would serve your community.

When a Member Dies

At some point, a known member of your community will die. This may be from a subsequent cardiac arrest, from related complications, from an unrelated illness, or from causes unconnected to their original arrest. How you handle this matters.

If you learn of a death:

- Verify the information before communicating it. Reach out to family if possible, both to confirm and to ask how they would like the news shared.
- Respect family wishes about what information to share and how.
- Make an announcement that honours the member while being sensitive to how this news will land on other members—particularly those still in early recovery.

Supporting the community:

- Allow space for grief. Members may have formed genuine connections with the person who died.
- Acknowledge the fear this may trigger. Other members will wonder: "Could this happen to me?"
- Consider whether a dedicated thread or temporary pinned post is appropriate.
- Watch for members who are particularly affected and may need additional support.

End-of-life discussions:

- Some older members will have end-of-life questions: ICD deactivation decisions, palliative care, quality versus quantity of life.
- These conversations can be difficult to host alongside recovery-focused content. Consider how to create appropriate space for them.

- Know your limits—end-of-life planning involves medical, legal, and deeply personal considerations that may exceed peer support scope.

Relationship and Family Impact

Cardiac arrest strains relationships. Your community will include members navigating this.

Relationships ending:

- Some marriages and partnerships do not survive the aftermath of cardiac arrest. Members may be dealing with separation or divorce on top of physical recovery.
- These members need support without judgment. Avoid framing that implies relationships "should" survive if people try hard enough.
- Co-survivor spaces may include partners who are separating from the survivor—this requires sensitive moderation.

Complex family dynamics:

- Adult children of survivors have distinct experiences—role reversal, fear of genetic risk, caregiver burden.
- Parents of young adult survivors face different challenges—watching a child navigate this at the start of their adult life.
- When both halves of a couple are in your groups and give conflicting accounts of their situation, stay neutral. You are not a mediator.

Sexual intimacy:

- Return to sexual activity is a common concern that survivors struggle to discuss. Fear of triggering another arrest, device-related concerns, medication side effects, psychological barriers, and relationship changes all play a role.
- If this topic arises in your community, treat it as the legitimate health concern it is. Many survivors find it easier to ask these questions in peer spaces than in clinical appointments.

Members with Pre-existing Mental Health Conditions

Cardiac arrest interacts with pre-existing mental health conditions in complex ways.

Common patterns:

- Pre-existing anxiety may intensify dramatically after cardiac arrest, sometimes to disabling levels.
- Depression may deepen, or may emerge in someone who was previously managing.
- OCD or health anxiety may focus obsessively on cardiac symptoms.
- Trauma responses may layer on top of existing PTSD.

Moderation considerations:

- Members with severe anxiety may post excessively, seeking constant reassurance. Gentle boundaries may be needed.
- Some members may need professional mental health support before or alongside peer support. Peer support is not a substitute for clinical care.
- Watch for members whose mental health appears to be deteriorating. A private check-in expressing concern may be appropriate.

Know the difference:

- A member with well-managed anxiety who experiences cardiac arrest and needs extra support: peer support is appropriate.
- A member in acute mental health crisis who happens to also be a cardiac arrest survivor: they need professional support first.

The Transition from Active Participation

Not everyone stays forever. Understanding healthy patterns of engagement helps.

Healthy "graduation":

- Some members recover, find their footing, and naturally drift away. This is success, not abandonment.
- Others transition from needing support to offering it, then eventually reduce involvement as other life priorities take over.
- Do not guilt members who leave. Celebrate that they are doing well enough to need you less.

Concerning departures:

- A member who was deeply engaged disappearing suddenly may warrant a quiet check-in.
- A member who leaves angrily after a conflict may need space, but consider whether anything could have been handled differently.

Long-term members who disengage:

- Some long-standing members become bitter, critical, or disengaged over time. This is worth exploring gently—burnout, disappointment, or personal difficulties may be factors.
- A member who was once valuable but is now consistently negative may need a private conversation about their experience.

Training and Safeguarding

Formal training:

The question of whether peer supporters and moderators should receive formal training has no single answer. Arguments exist on both sides:

For training:

- Structured skills in active listening, boundaries, and crisis response
- Confidence in handling difficult situations
- Demonstrable competence when working with healthcare partners
- Safeguarding awareness, particularly for vulnerable adults

Against over-formalising:

- Authenticity of lived experience can be diluted by professionalisation
- Training costs money and time that small organisations may not have
- The value of peer support lies partly in its informality

Our view: Basic safeguarding awareness is non-negotiable for anyone moderating vulnerable communities. Beyond that, training can be valuable but should not become a barrier to participation. Mental Health First Aid, trauma-informed approaches, and suicide awareness training all have value. But a caring, boundaried peer with no formal training is more valuable than a trained volunteer who has not lived the experience.

Safeguarding considerations:

- Know your country's safeguarding framework for vulnerable adults
- Have clear escalation paths for serious concerns
- Document significant incidents appropriately
- Understand confidentiality and its limits

Quick Reference

This section provides at-a-glance guidance for common situations. For more detailed resources, see:

- **Appendix A:** Complete group rules (adaptable template)
- **Appendix B:** Template messages for common moderation situations
- **Appendix C:** Crisis protocol (what to do when someone is in distress)
- **Appendix D:** Welcome content guide (orienting new members)
- **Appendix E:** Scripts for difficult conversations
- **Appendix F:** Free tools for getting things done
- **Appendix G:** Bereavement signposting (template and resources)

First Meetup: A Suggested Flow

You do not need a formal agenda. But this loose structure helps:

1. **Arrival and informal chat:** Let people settle with drinks and casual conversation.

2. **Introductions:** Each person briefly shares their connection to cardiac arrest—only as much as they are comfortable with.

3. **Open discussion:** Let conversation flow naturally. Common topics include: How did you find us? What has recovery been like? What do you wish you had known earlier?

4. **Wrap-up:** Thank everyone for coming. Mention the next meetup if planned. Remind people about the online community.

The goal is connection, not information transfer. Do not over-structure.

Moderation Decision Tree

A simple framework for thinking through moderation decisions. When you see concerning content, ask:

1. **Is this a safety concern?** (Expressions of self-harm, threats to others, crisis situations) → Respond immediately. Reach out privately. Follow your crisis protocol.

2. **Does this violate clear guidelines?** (Spam, promotion, medical advice-giving, abuse) → Remove and message the person explaining why.

3. **Is this a grey area?** (Borderline content, potential misunderstanding, new member unaware of norms) → Consider a gentle redirect rather than removal. Assume good intent first.

4. **Is this a conflict between members?** → Intervene privately first. Public moderation escalates conflict.

5. **Is this just uncomfortable but not wrong?** → Probably leave it. Peer support sometimes involves difficult emotions and uncomfortable truths.

Key Milestones Checklist

First month:

- Platform chosen and set up
- Basic guidelines written
- At least one other moderator identified
- First ten members joined
- Consistent posting rhythm established

First year:

- 50+ active members
- Clear community culture established
- At least one healthcare professional aware and referring
- Volunteer team of 3–5 people
- First in-person meetup (even if small)

Years 2–3:

- 200+ members
- Multiple regional meetups
- Formal relationships with some healthcare providers
- Consideration of organisational structure
- Documentation of processes and knowledge

Years 4+:

- Sustainable operations not dependent on founder
- Recognised voice in national conversations
- Research partnerships
- Stable funding (even if modest)
- Next generation of leadership developing

Signs of a healthy network: Beyond membership numbers, how do you know your network is functioning well? These simple indicators can help you—and anyone supporting you—understand whether things are working:

- *Response time to new members:* Are welcome posts acknowledged within 24 hours? Are questions answered within a day or two?
- *Moderator coverage:* Is someone checking the group daily? Are crisis posts being spotted promptly?
- *Member-initiated content:* Are members starting conversations, or does all activity depend on moderators?
- *Returning engagement:* Do people who join stay and participate, or do they vanish after their first post?
- *The shift from asking to offering:* Are members who once arrived with questions now answering others' questions? This progression—from seeking support to providing it—is one of the clearest signs of a healthy community.
- *Tone and culture:* Does the group feel warm and supportive? Would you want to join if you were newly diagnosed?

These are not formal metrics to report—they are questions to ask yourself regularly. If the answers start to concern you, that is a signal to investigate, not a sign of failure.

Simple metrics to track monthly: If you need to report to trustees, apply for grants, or demonstrate impact to healthcare partners, start tracking a few basic numbers each month:

- Total membership (and net change from previous month)
- New member requests received and approved
- Number of posts and comments (most platforms show this in admin tools)
- Event attendance (if you run meetups or online sessions)
- Volunteer hours (estimate if necessary)
- Any referrals from healthcare professionals (if you can identify them)

You do not need sophisticated analytics. A simple spreadsheet updated monthly is enough. The value is in spotting trends over time—growth, decline, or seasonal patterns—not in precise measurement. When someone asks "is this working?", having twelve months of basic data is far more persuasive than impressions alone.

When Things Go Wrong

This guide has focused on building something that works. But things will go wrong, and when they do, it helps to know you are not alone.

The group goes quiet. Activity drops. Posts go unanswered. New members join but do not engage. This happens to every community at some point. It does not mean you have failed—it means you have hit a plateau. The solution is usually to inject energy yourself: post a discussion question, share a story, welcome new members personally. Sometimes a quiet period is just that—a period. Activity often returns.

A significant conflict erupts. Two members clash publicly. Or a moderator and member. Or factions form. This is painful and can feel like the community is falling apart. It rarely is. Act quickly: take the conversation private, hear both sides, enforce your rules consistently, and do not be afraid to remove people who will not respect boundaries. Most members will never see the conflict or will forget it quickly. What they will remember is whether you handled it fairly.

A moderator burns out or behaves badly. Someone you trusted becomes part of the problem—exhausted, bitter, or no longer aligned with the group's values. This feels like betrayal, especially if they were with you from the start. But it happens. Follow your processes, have the difficult conversation, and remember that protecting the community comes first. Most moderators who become problematic are people who gave too much for too long. Compassion and firmness can coexist.

Someone in crisis. A member posts something that frightens you—suicidal ideation, severe distress, a situation you feel unequipped to handle. Your crisis protocol exists for this moment. Follow it. You are not a therapist and you are not responsible for fixing their life. Your job is to respond with care, connect them with professional resources, and support them as a peer. That is enough. It has to be.

A bad public incident. A journalist misquotes you. A complaint appears online. Someone blames the group for something that was not your fault. These moments feel catastrophic but rarely are. Respond calmly, correct factual errors, do not engage with bad-faith attacks, and remember that your reputation is built on years of consistent work, not one incident.

There will be times when you want to quit. There will be days—maybe weeks—when you wonder why you started this. When the emotional weight feels too heavy. When you resent the demands on your time. This is normal. It does not mean you should quit, but it does mean you need support. Talk to someone. Take a break if you can. Remember why you started. And know that every founder of every successful peer support network has felt exactly this way.

None of these situations mean you have failed. They mean you are doing real work in the real world, with real people who have real problems. The goal is not to avoid difficulty—it is to navigate it without losing yourself or abandoning the people who depend on what you have built.

A note on the journey: This guide is written from a position of relative success—a decade in, with a thriving community and established partnerships. But it was not always like this. There were years when growth was slow, when we questioned whether we were making any difference, when the emotional toll felt disproportionate to the visible impact. The path from founding to maturity is not smooth or linear.

We cannot point to dramatic failures because we kept going, adjusted, and learned. But we know that not every initiative will follow this path. Some will remain small, and that is fine—a small group that genuinely helps people is still valuable. Some will struggle to find momentum and may eventually close. That is not shameful; it is the reality of volunteer-led work in a difficult space. The absence of a thriving peer support network is not evidence that someone failed—it may simply mean the conditions were not right, the timing was wrong, or the founder needed to step back for their own wellbeing.

If you start something and it does not grow, or if you need to stop, that does not erase the value of what you did. Every person you helped along the way was worth the effort.

Final Thoughts

Eleven years after starting SCA UK, we still receive messages from people saying, "I wish I had found you sooner."

Every one of those messages represents a gap we need to close. There are survivors and co-survivors in every country who feel alone, who think no one understands, who wonder if what they are experiencing is normal. They need to find each other.

You do not need to build something as large as SCA UK. A small, well-run peer support group that genuinely helps fifty people is worth more than a large organisation that looks impressive but does not actually work. Start with what you can do. Build from there.

The work is hard. It will take more time than you expect, more emotional energy than you anticipate, more patience than you think you have. There will be moments when you wonder why you bother.

And then someone will tell you that finding your community changed their life. That they felt less alone for the first time since their arrest. That your network gave them hope.

That is why we do this.

Go light your fire.

About Sudden Cardiac Arrest UK

The information in this section reflects SCA UK as of early 2026. For current details, visit suddencardiacarrestuk.org.

Sudden Cardiac Arrest UK was founded in 2015 and has grown into what is, to our knowledge, the world's largest national cardiac arrest survivorship organisation, with over 4,000 members across the United Kingdom. In November 2022, with support from the Resuscitation Council UK, SCA UK was established as a registered charity.

We provide peer support for survivors and co-survivors through online communities, regional meetups, and a national conference. We contribute to medical research and guidelines, advocate for better post-resuscitation care, and work to raise awareness of sudden cardiac arrest and the importance of bystander CPR.

Our communities:

- **Sudden Cardiac Arrest UK** — for survivors
- **Chain of Survival UK** — for co-survivors

Milestones:

- February 2015: First meetup at the Mulberry Bush pub, London (13 attendees)
- May 2015: Creation of Facebook group that becomes Sudden Cardiac Arrest UK
- February 2016: Second meetup and Up at The O2 walk
- November 2016: SCA UK members attend SADS UK "Life After Cardiac Arrest" event
- 2017: Two London meetups including largest gathering at Mulberry Bush; ArcelorMittal Orbit abseil challenge; SCA UK members speak at SADS UK conference
- 2018: Regional meetups in Bristol and Birmingham; Guinness World Record—127 cardiac arrest survivors gathered at the Essex Cardiothoracic Centre; *Life After Cardiac Arrest* book published; "Life After Cardiac Arrest" podcast launched
- 2019: "Not Alone" national conference, Rutland
- 2020: *Life After Cardiac Arrest Volume 2* published; podcast paused
- November 2022: SCA UK registered as charity
- 2023: "Survive and Thrive" national conference, Daventry; American Heart Association International Collaboration Award
- September 2024: Resuscitation Council UK publishes Survivors Quality Standards (SCA UK contributed to development)
- 2025: "10 Years Together" national conference; podcast relaunched; contribution to European Resuscitation Council guidelines—Paul Swindell (Ethics and Post-Resuscitation Care chapters, including establishing "co-survivor" terminology), Gareth Cole (Advanced Life Support chapter), and Josephine Henderson (Paediatric chapter)

Our publications:

We have developed a range of resources to support survivors, co-survivors, and healthcare professionals:

- *Life After Cardiac Arrest* book series (Volumes 1 and 2)
- *SCA UK Effective Peer Support Information* leaflet — introduction to our organisation for hospitals and clinical settings
- *Chain of Survival* leaflet — for those who have witnessed or been involved in a resuscitation attempt
- *I Care* leaflet — for partners, family, and friends of survivors
- *Managing Fatigue* leaflet — guidance from occupational therapy expert Donna Malley
- *Cognitive Problems* leaflet — information on common cognitive challenges after cardiac arrest
- *Mental Health Well-being* leaflet — support for psychological recovery

Our podcast:

The *Life After Cardiac Arrest* podcast features over sixty episodes with survivors, co-survivors, clinicians, researchers, and innovators—exploring the full breadth of life after sudden cardiac arrest.

Find us online:

- Website: suddencardiacarrestuk.org
- Facebook: facebook.com/groups/SuddenCardiacArrestUK
- Podcast: shows.acast.com/life-after-cardiac-arrest

Registered Charity Number: 1200875

What Our Members Say

"I found this group, a group that I never wanted to join until I had my own SCA in September 2021. This group really was a lifeline in those early, vulnerable months when everything was scary and uncertain. I asked questions, sought advice and I soon realised that there was always someone there to help, no matter what time of the day or night. There were no silly questions, it became clear it was only silly not to ask them. Within a few months I felt stronger, more resilient and could see a light at the end of the tunnel. The opportunity to meet other survivors came soon after joining as there are members all around the UK to take the lead in setting up meetings. Attending a meet up made me feel safe, understood and connected. Sharing experiences brings deep empathy. I cannot speak highly enough of Sudden Cardiac Arrest UK."

— Shem

"This group were a true lifeline for me when my hubby had an out of hospital cardiac arrest back in April and I performed CPR. They gave me support and love and gave me hope when I thought there was none. In addition extremely knowledgeable database to draw upon. Highly recommended from the bottom of my heart."

— Lorraine V

"This is a fantastic support network. This helped me so much over the years but especially in the scary time after I was discharged from hospital. It is great to be able to compare with other survivors of things we go through that only those that have gone through it can understand. It was also amazing going to a meet up to hear other survivors' stories and meet other survivors. It really does help."

— Rachel D

"A wonderful supportive safe place for people who have experienced a sudden cardiac arrest and those who help them. A resource of real life experience and knowledge that is unique and invaluable for those who have been through sudden cardiac arrest and 'just get it'. Everyone I have met through this charity has been generous, uplifting and supportive. Their contribution to improve the lives of survivors is both unique and wide reaching."

— Rob L

"As a cardiac arrest survivor, I felt very alone, especially in the middle of the night when the demons get in. This group is always there with something helpful to say and makes a huge difference. If you know anyone who has experienced a sudden cardiac arrest, please tell them about the group. It is life changing."

— Sam T

"If you have suffered, or witnessed, a sudden cardiac arrest this support group is for you. When you leave hospital the support that you get from this group is exactly what you need whether you are a survivor or a witness, or if you participated in a resuscitation event."

— Jeremy H

"This charity has literally saved me. I have never felt so alone after my cardiac arrest as nobody really gets it unless it's happened to them. I found the Facebook group they set up and it's just amazing. Helped me understand that my feelings and emotions are perfectly normal after a life changing event. Still in the group and still getting the support and learning and understanding. Thank you!"

— Pat B

"I recently had a cardiac arrest and I was looking to gain some information but also because my 16 yr old daughter was the one who had to deal with ambulance and watching me having a cardiac arrest and then being brought back to life. So I wanted to see if anyone else had this experience and if I can get advice how to deal with the trauma. The group is amazing! Everyone is helpful and supportive. It's like a big family ❤️"

— Livia W

"When I had my out of hospital cardiac arrest I felt so alone with no one to talk to. Then I found Sudden Cardiac Arrest UK and my whole life changed. Having someone who's actually been through this massive event to talk to, reassure that what I was feeling was totally normal. I 100% recommend this invaluable organisation to anyone and everyone who is a survivor of this sometimes life changing event."

— Caroline F

"This site gave both myself and my husband all the support and information we needed to overcome my husband's sudden cardiac arrest in 2021. The psychological impact of such an event is too easily dismissed. Without full mental recovery there can be no full physical recovery. I have been so impressed with everything they do and that they were there when needed."

— Joanne P

"There is absolutely no substitute for having an enormous wealth of knowledge on your back door. That is exactly what the SCA family is. We have all started from the same place, whether as a survivor or a family member. It can be a long journey, but is now not so lonely."

— David K

"Best support group I could ever have wished for. Five years on and still learning from member comments and the fantastic library of information available."

— Freddie D

Appendix A: SCA UK Group Rules

These are the rules we use for our main Facebook community. Adapt them to your context, but the principles behind them are broadly transferable.

1. Be Kind and Courteous

We're all in this together to create a welcoming environment. Let's treat everyone with respect. Healthy debates are natural, but kindness is required, and bullying of any kind will not be tolerated.

2. No Hate Speech or Bullying

Make sure everyone feels safe. Bullying of any kind isn't allowed, and degrading comments about things like race, religion, culture, sexual orientation, gender or identity will not be tolerated.

3. Respect Everyone's Privacy

Being part of this group requires mutual trust. Authentic, expressive discussions make it thrive, but it must also be sensitive and private. What's shared in the group should stay in the group. Use the Anonymous post feature judiciously.

4. Do Not Offer Medical Advice

Please don't offer medical advice or attempt to diagnose other members' conditions. Do not rely on the medical advice of other members. Seek professional help from your doctor, visit a hospital, or contact your local health advisory service.

5. No Direct Messaging Without a Prior Relationship

You should only directly message another member once you have an established relationship, e.g., if you have met in person or had previously prolonged interactions within our groups or events. NB: This does not apply to group moderators.

6. Only SCA UK Events/Campaigns to be Advertised

Third-party events, including sponsorship campaigns, are not allowed. The events section of the group is reserved exclusively for SCA UK events.

7. No Promotions, Commercials, Spam or Fundraising

Please give more than you take. Commercial enterprises, self-promotion, spam and irrelevant links aren't allowed unless previously agreed. This includes charity and fundraising, except for SCA UK.

8. Posts Where Validity is Unclear or Potentially Harmful

We will remove all posts where the source or validity is unclear or potentially harmful. This covers medically related posts, including Coronavirus and non-evidence-based therapies.

9. Check for Similar Posts

Please make sure to search for similar posts before posting about common topics such as driving, insurance, trending media stories, or memes. Check recent posts and group guidelines, and use the search tool.

Appendix B: Template Messages

These are examples of standard messages we use for common moderation situations. Adapt them to your own voice and context.

Declining an anonymous post:

"Dear [Name], SCA UK works hard to create a safe and supportive environment for its members and wants to restrict the use of anonymous posts. By posting with your name, we feel you will get more personal responses. We do not feel that this post needs to be anonymous."

Declining a membership request (non-UK):

"SCA UK is a group for UK citizens or ex-pats only. We recommend you try linking up with other groups that support your country."

Declining a membership request (bereaved):

"We are sorry for your loss. SCA UK is for survivors and their close family only. Please refer to our bereavement guidance at scauk.org/bereavement. You may also find support in our sister group Chain of Survival UK."

Declining a membership request (bystander/CPR provider):

"SCA UK is a group for survivors or their close relations only. If you were involved in or witnessed a resuscitation attempt, we recommend you join our sister group Chain of Survival UK."

Declining a membership request (medical professional):

"SCA UK is a group for survivors that enables survivors to talk openly about their experiences in a safe environment. We do not admit those whose interest is primarily professional."

Clarifying heart attack vs cardiac arrest:

"SCA UK is a group for those who have suffered a cardiac arrest, which is different from a heart attack. If, having understood the difference, you had a cardiac arrest, please re-apply."

Welcome message:

"Please join me in welcoming our newest member(s) [Names]. Please view the information at scauk.org/welcome"

Appendix C: Crisis Protocol

When a member posts content suggesting they may be in crisis—expressing suicidal thoughts, self-harm, or severe distress—you need to act quickly but calmly. This protocol gives you a framework. Adapt it to your context and local emergency services.

Immediate steps:

1. **Do not delete the post immediately.** It may be needed by emergency services, and deletion can feel like rejection to someone in crisis.

2. **Take a screenshot.** Document what was posted, when, and by whom. You may need this information later.

3. **Respond publicly with warmth.** A brief, caring comment lets them know they have been seen: "I'm so sorry you're feeling this way. You're not alone. I'm sending you a private message now."

4. **Message them privately.** Use a script like this:

"I saw your post and I'm concerned about you. How are you doing right now? If you're having thoughts of harming yourself, please reach out to [your country's crisis line] or go to your nearest emergency department. You matter to this community, and we want you to get the support you need."

5. **Do not promise confidentiality you cannot keep.** If you believe someone is in imminent danger, you may need to involve emergency services.

If you believe risk is imminent:

If the person has shared their location (or you can identify it from their profile) and you genuinely believe they are about to harm themselves, contact your local emergency services. They can conduct a welfare check. If you only have a name and general location, emergency services may still be able to help.

In the UK, call 999 for emergencies or 101 (police non-emergency) for advice if you are unsure.

This is a serious step. Use your judgement. Err on the side of caution—a welfare check that turns out to be unnecessary is far better than inaction when someone needed help.

After the immediate crisis:

- Check in with the member over the following days if they remain in the group.
- Signpost them to professional support (crisis lines, their doctor, counselling services).
- Debrief with your moderator team. Processing these situations together is important.
- Look after yourself. Witnessing someone else's crisis is distressing. Talk to someone you trust.

What NOT to do:

- Do not ignore it and hope someone else will handle it.
- Do not lecture or minimise ("Others have it worse").
- Do not share details of the crisis with the wider group.
- Do not feel you must solve their problems. Your job is to connect them with help, not to be their therapist.

Crisis resources to have ready:

Build a list of crisis resources for your country before you need them. Keep these pinned in your moderators' group so anyone on duty can access them quickly.

In the UK:

- Samaritans: 116 123 (free, 24/7)
- Crisis text line: Text "SHOUT" to 85258
- NHS urgent mental health support: 111, option 2
- Emergency services: 999

Appendix D: Welcome Content Guide

When someone joins your group, they need orientation. Whether you direct them to a website, a pinned post, or a welcome message, here is what that content should include.

Essential elements:

1. **What the group is for**

A brief statement of purpose: "This is a peer support community for cardiac arrest survivors. We share experiences, ask questions, and support each other."

2. **What the group is NOT for**

Set expectations: "We are not medical professionals. Nothing here should be taken as medical advice. For health concerns, contact your doctor or local health service."

3. **Group rules summary**

Either list the key rules or link to them. Highlight the most important: be kind, respect privacy, no medical advice-giving.

4. **How to get started**

Encourage new members to introduce themselves: "When you're ready, feel free to post and tell us a bit about yourself and your connection to cardiac arrest. There's no pressure—share as much or as little as you're comfortable with."

5. **How to find information**

Point them to the search function: "Before posting a question, try searching the group—chances are it's been discussed before. Topics like driving, insurance, and travel come up regularly."

6. **Key resources**

Link to your most useful content. As you grow, this might include:

- Information pages (driving regulations, returning to work, emotional recovery)
- Publications or leaflets
- Podcast or video content
- Partner organisations for specialist support

7. **Sister groups or related communities**

If you have separate spaces for co-survivors, bereaved members, or specific topics, mention them here with links.

8. **Social media**

If you have presence on other platforms, invite them to follow: "Help us spread the word by following us on [platforms]."

Example welcome content (adapt to your context):

"Welcome to [Group Name]—a friendly, private community for cardiac arrest survivors.

Getting started:

- Read our group rules [link]
- Introduce yourself when you're ready
- Use the search bar for common topics (driving, insurance, travel)

Important:

We are a peer support group, not medical professionals. For health concerns, contact your doctor or [local health service].

Resources:

- [Link to key information]
- [Link to publications]
- [Link to podcast/videos]

For co-survivors and CPR givers:

Our sister group [Name] is dedicated to supporting those who witnessed or responded to a cardiac arrest. [Link]

Follow us:

- [Social media links]

You're not alone. We're glad you found us."

Visual welcome content:

As your resources grow, consider creating a visual welcome—an animated GIF or short video that cycles through key information. This can be more engaging than text alone and works well on mobile. Our welcome GIF includes:

- Welcome message and confirmation this is a private group
- Pointer to our "start here" page
- Reminder that CPR givers, co-survivors, and partners should also join our sister group
- Quick links to key resources (publications, driving information, counselling, bereavement support, ICD information, podcast)
- Social media links with a call to follow and support

This visual approach shows newcomers the breadth of what you offer at a glance, while keeping the detail on your website where it can be updated easily.

Appendix E: Difficult Conversations

Scripts for conversations no one wants to have.

Asking a moderator to step down:

This is one of the hardest conversations you will face. The person likely started as a valued volunteer and may still see themselves that way. Approach with compassion but clarity.

Example script:

"I wanted to have an honest conversation with you about your moderator role. I've noticed that things seem to have shifted lately—[specific observation: tone in responses has become sharper / you seem less present / there have been several complaints from members].

I want to check in: how are you doing? Is everything okay?

[Listen to their response]

I'm grateful for everything you've contributed to this community. But I think the role may not be working for you right now—or for the group. I'd like to suggest you step back from moderating for a while and just be a member. Take the pressure off.

This isn't a punishment. It's about protecting you from burnout and making sure the group culture stays where it needs to be. You're still welcome here, and I hope you'll stay involved as a member.

What do you think?"

Key principles:

- Be specific about what you've observed, not vague accusations
- Ask how they're doing—there may be personal circumstances
- Frame it as protecting them, not punishing them
- Offer a path to remain in the community as a member
- Be prepared for them to be upset or defensive
- Follow up in writing so there's a record

If they react badly:

Some people will not take this well. They may argue, accuse you of unfairness, or leave the group entirely. This is painful but sometimes unavoidable.

- Stay calm and do not get drawn into argument
- Reiterate that the decision is made and is final
- Thank them again for their past contribution

- If they become abusive, end the conversation

Declining a membership request (sensitive cases):

Sometimes you need to decline someone who clearly needs support but doesn't fit your group's criteria—for example, a bereaved person applying to a survivors-only group.

Example script:

"Thank you for your request to join [Group Name]. I'm so sorry for your loss.

Our group is specifically for cardiac arrest survivors and their immediate family. We've found that mixing bereaved members with survivors can be difficult for both—survivors can find it distressing to encounter stories where the person didn't make it, and bereaved members deserve dedicated support from others who understand their specific experience.

I'd like to point you to [Bereavement organisation] who offer support specifically for people in your situation. You might also find our sister group [Name] helpful, which welcomes anyone affected by cardiac arrest including bereaved family members.

I know this isn't the answer you were hoping for, and I'm sorry we can't welcome you here. Please do reach out to the organisations above—you deserve support."

De-escalating conflict between members:

Sometimes two well-meaning members clash—not because either is breaking rules, but because they have different perspectives on recovery, faith, medicine, or coping. Your job is not to pick a winner but to validate both while keeping the space safe.

Example script (public comment):

"I can see this topic has touched on some deeply personal experiences for both of you. [Name1], it sounds like [approach] has been really important to your recovery. [Name2], I hear that your experience has been different, and that's equally valid.

One of the things that makes this community work is that we hold space for different paths. What helped one person may not help another, and that's okay. We're all finding our own way.

Let's take a breath here. You're both valued members of this group, and I'd hate to see a disagreement overshadow that."

Example script (private message if needed):

"I noticed the discussion with [Name] got a bit heated. I wanted to check in—are you okay?

I understand why [their perspective] might be frustrating when it doesn't match your experience. In this group, we try to hold space for different approaches, even when we personally disagree. That doesn't mean your perspective is wrong—just that others may have found different things helpful.

Thanks for being part of this community. Let me know if you want to talk it through."

Key principles for de-escalation:

- Validate both parties' experiences without declaring a winner
- Name what's happening calmly ("I can see this has become heated")
- Remind everyone of shared purpose
- Move to private messages if the public thread is escalating
- Know when to close comments—sometimes the kindest thing is to end the conversation

Appendix F: Free Tools for Getting Things Done

You do not need a budget to run a peer support network professionally. Many powerful tools are available free, and learning to use them well can save you thousands in software costs and design fees.

Note: Tool features and pricing tiers change frequently. The information below was accurate at the time of writing but may have changed. Check current offerings before committing to any platform.

Documents and collaboration:

- **Google Docs, Sheets, and Slides** — Free with a Google account. Create documents, spreadsheets, and presentations that multiple people can edit simultaneously. Essential for collaborative writing, shared planning, and working with volunteers remotely.
- **Google Drive** — Free cloud storage (15GB) for organising and sharing files. Create shared folders for your moderator team or trustees.
- **Google Forms** — Create surveys, feedback forms, registration forms, and questionnaires for free. Responses automatically populate a spreadsheet. Invaluable for gathering member input, event sign-ups, or simple research.

Design and visual content:

- **Canva** — Free design tool with templates for social media posts, leaflets, presentations, posters, and more. The free tier is generous; most peer support networks will never need the paid version. We use Canva for almost all our visual materials.
- **Remove.bg** — Free tool to remove backgrounds from images, useful for creating clean graphics.

Communication:

- **Mailchimp** — Free for up to 500 contacts. Send newsletters, updates, and announcements to your mailing list with professional templates.
- **WhatsApp or Signal groups** — Free messaging for moderator coordination or regional organiser communication.

Scheduling and organisation:

- **Google Calendar** — Free shared calendars for events, moderator rotas, and deadlines.
- **Doodle or When2meet** — Free tools for finding meeting times that work for everyone.
- **Trello or Notion** — Free project management tools if you need to track tasks across a team.

Video and meetings:

- **Zoom** — Free for meetings up to 40 minutes (often enough for quick catch-ups); longer for one-to-one calls.

- **Google Meet** — Free video meetings with a Google account, no time limit for one-to-one calls.
- **OBS Studio** — Free software for recording videos or livestreaming, if you want to create content.

Content creation:

- **Your smartphone** — Modern phones record perfectly good video for YouTube. Natural lighting, a quiet room, and a simple tripod or stack of books is all you need to start.
- **Spotify for Creators** (formerly Anchor) — Free app to record, edit, and publish podcasts directly from your phone. Distributes automatically to Spotify, Apple Podcasts, and other platforms.
- **Audacity** — Free audio editing software for computers. More control than phone apps if you want to polish your recordings.

Website (if you need one later):

- **WordPress.com** — Free basic websites. Limited customisation, but enough to establish a web presence.
- **Carrd** — Free single-page websites, good for a simple landing page with links to your groups and resources.

Useful links:

- **ILCOR (International Liaison Committee on Resuscitation)** — ilcor.org/about — includes a list of national resuscitation councils worldwide. If you are starting a network and want to connect with the resuscitation community in your country, this is a good starting point.
- **ERC Cardiac Arrest Dashboard** — cpr-dashboard.erc.edu — European data on cardiac arrest incidence, survival rates, and outcomes by country. Useful for understanding the landscape in your region and for making the case to healthcare partners.

Other survivor organisations:

You are not alone in this work. Other cardiac arrest survivor networks exist around the world, and connecting with them can provide solidarity, shared learning, and potential collaboration. A 2025 European Resuscitation Council survey identified only eight organisations globally providing structured, continuous support for cardiac arrest survivors—a striking gap given the scale of need. At the time of writing, these include:

- **United States:** Cardiac Arrest Survivors Alliance (CASA) — casahearts.org; OurHeartsight — ourheartsight.com; Sudden Cardiac Arrest Foundation (SCAF) — sca-aware.org
- **Sweden:** Hjärtstoppsöverlevare — hjartstoppsoverlevare.se; The Swedish Network for Cardiac Arrest Survivors and Relatives — hjart-lung.se/natverket-for-overlevare/
- **Belgium (international):** Heart Warrior Project — heartwarriorproject.com
- **Austria:** PULS – Austrian Cardiac Arrest Awareness Association

- **Italy:** Fondazione IRC — fondazioneirc.org
- **Switzerland:** Swiss Heart Foundation — swissheart.ch
- **Finland:** Finnish Heart Association — sydan.fi
- **International:** SCA Survivors Facebook Group — facebook.com/groups/scasurvivors

This list is not exhaustive, and new groups emerge regularly. If you are starting a network, reaching out to existing organisations can help you learn from their experience. The ERC survey found that most survivor organisations were established after 2000, typically rely on donations and private funding, and offer peer support (88%), informational materials (75%), and research collaboration (88%) as their core activities.

Related UK cardiac organisations:

While not specific to cardiac arrest survivors, these UK organisations offer peer support for related cardiac conditions and may be useful partners or referral points:

- **Cardiomyopathy UK** — cardiomyopathy.org — operates "Heart to Heart" peer support network
- **Arrhythmia Alliance** — heartrhythmalliance.org — includes AF-CARE peer support
- **Chest Heart & Stroke Scotland** — chss.org.uk — peer support groups across Scotland
- **British Heart Foundation** — bhf.org.uk — patient support and information resources

Appendix G: Bereavement Signposting

If your network supports co-survivors who witnessed a resuscitation where the patient did not survive, you will need a clear pathway to bereavement support. This appendix provides a template based on how we handle this at SCA UK.

The key principle: You can support people processing the trauma of the resuscitation event itself—the CPR, the waiting, the questions about whether they did enough. But ongoing bereavement support requires specialist skills and resources that a survivor-led peer network is not equipped to provide. Being clear about this boundary is not rejection; it is responsible care.

Template: Bereavement Information Page

Adapt this for your website or welcome materials:

When someone dies suddenly

When someone dies suddenly and unexpectedly, you might hear it called a cardiac arrest, a heart attack, sudden cardiac death, or sudden arrhythmic death syndrome (SADS).

Dealing with the death of a loved one is one of the hardest things any of us will have to face. If someone close to you dies unexpectedly, it is natural to ask why and how it could have happened, particularly if they were young or seemed perfectly healthy.

[Your organisation name] was established to provide peer support for survivors and others affected by the survivor's cardiac arrest. We are not equipped or trained to provide ongoing bereavement support, but we want to help you find the right support for your needs.

If you witnessed or participated in the resuscitation

If you were involved in or witnessed a resuscitation attempt—performing CPR, calling for help, fetching the defibrillator, waiting while others worked—you may find it helpful to connect with others who have been through similar experiences, regardless of the outcome. Processing the trauma of that event is something we can help with.

[Link to your co-survivor group or Chain of Survival equivalent]

Bereavement support organisations

If you are dealing with bereavement and need ongoing support, we recommend contacting one of the following organisations, which are better equipped to meet your needs:

[List organisations in your country - see categories below]

Categories to Include

When building your bereavement signposting page, consider including:

General bereavement support

- National bereavement charities
- Telephone helplines with extended hours
- Online forums and peer support communities
- Counselling services (noting any costs or waiting times)

Cardiac-specific bereavement

- Heart charities that offer bereavement support
- Organisations focused on sudden cardiac death or inherited conditions
- Support for families awaiting post-mortem or inquest results

Child bereavement

- Support for bereaved children and young people
- Support for parents who have lost a child
- School and educational resources

Finding services in your country

- Your national health service may have bereavement pathways
- Hospice organisations often provide community bereavement support
- Religious and community organisations may offer local support
- Your national resuscitation council may know of relevant organisations

UK Examples (for reference)

These are the organisations we signpost to in the UK. Use them as a starting point for identifying equivalents in your country:

General bereavement:

- Cruse Bereavement Care (national charity with helpline)
- The Compassionate Friends (support for bereaved families)
- At a Loss (directory of bereavement services)

Cardiac-specific:

- British Heart Foundation (heart charity with bereavement resources)
- SADS UK (sudden arrhythmic death syndrome—supports affected families)

Child bereavement:

- Child Bereavement UK (when a child dies or faces bereavement)
- Winston's Wish (grief support for children)

- Hope Again (Cruse's service for young people)

Communicating with Sensitivity

When someone contacts your network following a death, they may be in acute distress. How you respond matters.

Do:

- Acknowledge their loss with compassion
- Explain clearly what support you can and cannot offer
- If they witnessed the resuscitation, invite them to your co-survivor space for help processing that specific experience
- Provide direct links to bereavement organisations—do not just say "search online"
- Follow up if appropriate to check they found support

Do not:

- Simply reject them or say "we can't help"
- Assume they only need bereavement support—they may also need to process the resuscitation trauma
- Provide bereavement counselling yourself if you are not trained to do so
- Leave them without a clear next step

Sample response:

"I'm so sorry for your loss. [Your organisation] provides peer support for cardiac arrest survivors and those who witnessed or participated in resuscitation events. While we're not able to provide ongoing bereavement support, we can help in two ways:

If you were present during the resuscitation attempt and would find it helpful to connect with others who have been through similar experiences, our [co-survivor group name] welcomes people regardless of outcome. Many people find it helps to process that traumatic experience with others who understand.

For ongoing bereavement support, I'd recommend [specific organisation] who specialise in supporting people through grief. Their helpline is [number] and they offer [brief description of services].

Please don't hesitate to reach out if you have questions about either pathway."

"A candle loses nothing by lighting another candle."

— James Keller