Arrhythmia Alliance
www.heartrhythmalliance.org

Patient Advocacy Toolkit

A Step-by-Step Guide to Advocacy

"Advocacy is speaking up for those who cannot speak for themselves"

www.heartrhythmalliance.org

Welcome to Patient Advocacy

This toolkit is for everyone who has a passion for improving the lives of people living with cardiovascular disease (CVD) and wants to learn more about what you can do to improve the situation.

Whether you are affected yourself, or are a family member, caregiver or healthcare professional, your voice can make an important impact. The toolkit offers practical advice to equip you to fight for better care and treatment options for people living with CVD – in other words, to become a patient advocate.

Advocacy is a grassroots effort and starts with you!

Before you can become an advocate for others, it is important that you are empowered to be your own best advocate. Once you feel empowered to be a part of your healthcare team and share in decisions, you are ready to help empower others. The magic happens when groups of empowered advocates come together and be the voice of others who do not have a voice.

We look forward to working with you and helping you develop into a patient advocate. This toolkit is your first step as you prepare for the training.

1 **Advocating for yourself**

2 **Empowering others to advocate**

3 **Advocating for those who have no voice**

3 STAGES OF ADVOCACY

GETTING STARTED:

A five step plan to deliver effective advocacy.

When getting started in advocacy, there are five key questions to ask yourself:

1

What is my story and how much do I want to share?

2

What is the impact of my condition in my local/national context?

3

What would I like to achieve? What is my personal goal?

4

Who are the key people who can help me achieve this goal?

5

What messages and methods are required to reach this audience?

This toolkit offers a step-by-step approach to answering these questions and the worksheet will guide you through them all. During your training we will deep dive into all these topics so do not worry if you do not have all the answers yet. This toolkit and the accompanying worksheets are designed to give you time to think and prepare yourself for your work.

Let's get started!

STEP 1:

Know your story

The most important part of advocacy is your story.

Your story is impactful and can provide not only inspiration but also support to others. Each person has a unique story and sharing the impact your diagnosis has made in your life, and the lives of those around you can be vital to succeeding in advocacy.

Statistics and facts can be shared and are easily obtainable by decision makers. However, when a person living with the condition shares their story it can spark the emotion and put what it actually means to be diagnosed and live with the condition in the hearts and minds of those decision makers. The effect is powerful.

Spend some time writing out your story. Take the time to remember the times that you struggled and what would have been helpful to you during that time. You may also remember a time that you had a good experience and can provide that as an example of good care. As you refine your story for different audiences you may find that you share certain parts of it at various times, and that is ok, but spend some time writing it all out and think about how you might use your voice to make a difference. It is also important to think about how living with your condition has affected your work life and your family.

Remember the times that you struggled. What would have been helpful to you during that time?

Remember a time that you had a good experience. Provide that as an example of good care.

Throughout your training with Arrhythmia Alliance you will have the opportunity to refine your story and tailor the message to your audience. We will guide you in crafting your message and empower you to confidently tell it. This first step is about writing out your story, and what makes you special.

Complete your story on the next page

How has living with your condition affected your work life and your family?

STEP 1: WORKSHEET

Know your story

I was diagnosed with: (Add a little about your condition and when you were diagnosed)

When I was diagnosed, I felt: (Use words to describe your feelings: e.g. scared, confused)

The hardest part of living with my condition is:

My diagnosis has impacted my mental health by:

My diagnosis has impacted my family/work life in these ways:

I wish I had: (What would have helped you or would help you now?)

It is important for people to understand: (What do you want people to know or understand?)

I am hopeful because:

STEP 2:

Explore the impact of your condition in your country/ community

Using facts and statistics about your condition

This is a wonderful way to persuade decision-makers to care about the issue – but only if this information is relevant to them.

There will be times that you need to know how your condition impacts your local community, the hospital or healthcare area that you live, or maybe the city/country.

For example, a politician has a constituency to serve, so they are far more likely to care about how your condition affects their constituents than about the US or global statistics. For this reason, you will need to find out as much as you can about your condition in the context of your state or community.

As you work through your training with Arrhythmia Alliance, we will help guide you in the right direction to find resources and impact on your condition.

Some things that you might want to research:

- How are decisions related to healthcare made in your area?
- How can individuals participate in policymaking processes and influence policymakers?
- Are decisions made by the US Congress or does your state make certain decision?
- Who has the power to influence these decisions?
- What is the responsibility of local/ state authorities?

Fill out the worksheet on the next page to complete this section

STEP 2: WORKSHEET

Explore the impact of your condition in your country/ community

My condition is:

I can find out more information about my condition from:

How does my condition impact my community?:

(e.g. How many people in your state live with your condition?)

Is there a current national strategy or what work is being done currently in my state?:

What gaps are there that need to be addressed in my community?:

STEP 3:

Define your advocacy goals

What does advocacy success look like for you?

It might be as simple as supporting others, raising awareness or getting a reply to your social media post. Some people may want to set goals about putting a poster up in your local physicians' office, supermarket, or local health centre. Or it could be as big as getting a politician to champion legislative changes to support your cause!

Regardless of how big your goals are, it will help you to have clear, achievable steps, or objectives. Think of your objectives as a roadmap to your goals.

Throughout the training you will have support in developing your advocacy goals.

Your goals may look something like these:

1. Share my story to support and empower others
2. Help my local hospital to improve patient care
3. Bring awareness to my condition
4. Meet with policy makers to help bring systemic change

For a goal to be obtainable and workable, you should follow the guide of a **SMART** goal. This plan will help you assure that your goals are able to be reached.

SPECIFIC:

What do you want? Who needs to be involved? How and/or where will it happen?

MEASURABLE:

How will you track progress and know when you've achieved your objective?

ACHIEVABLE:

Is your objective realistic with the resources you have?

RELEVANT:

Is this objective aligned with your main goal (e.g. to improve diagnosis, care and quality of life for people with AF)?

TIME-BOUND:

When do you want to achieve this? Setting a deadline can help you to plan activities and inspire others to act.

Complete the worksheet section on the next page to help define your advocacy goals

STEP 3: WORKSHEET

Define your advocacy goals

With the **SMART** goals in mind, answer these questions:

I want to:

To be successful I need to engage with:

I will be successful if:

Is my goal achievable? If not, why?:

How will my goal support the mission of improving the lives of others?:

What is my deadline for achieving my goal?:

Are there smaller goals that can help to advance my larger goal?:

STEP 4:

Identify the people who matter

Stakeholder is a word used to describe a person who has interest in a topic.

There are many stakeholders in healthcare. From those living with the condition, patient organisations, healthcare professionals who treat them, the decision makers, and even community leaders.

It is important to understand which individuals and organisations can help you achieve your goals. These may include government officials and employees, healthcare professionals and their professional societies, and patient advocacy groups.

Depending on your advocacy goal you may need to engage with healthcare professionals in your local community. Physicians, nurses, or administrators may be important to your goal.

Patient organization, such as Arrhythmia Alliance, are important because they can help you identify the scope of issues that are important to you and also help you use your voice effectively as a group.

Engaging with policymakers may be extremely helpful, depending on what you set out to achieve, because they shape our health systems. They are also keen to understand the issues that matter most to individuals and how they can facilitate positive change. It is therefore important to make policymakers aware of the realities and needs of people living with CVD and the issues around diagnosis and care. Other key players are also important, not least because they may be able to help you and your message reach policymakers.

Complete the worksheet section on the next page for ways to determine who are the key decision makers whom you might prioritise engaging on page.

STEP 4: WORKSHEET

Identify the people who matter

Ask yourself these questions about each of them, to identify the individuals who are most useful to target in your advocacy efforts:

- What is this person's main interest?
- How influential are they?
- Are they likely to support your goals?

Who are the stakeholders in my community?:

What is the person's main interest in my goal?:

Who will most likely support my goal?:

Why would they want to support my goal?:

What is their benefit in supporting my goal?:

STEP 5:

Engage key individuals to support your cause

To win people's support, you will need clear and effective messages, delivered in a way that will reach your target audience.

The message

When you communicate with people such as officials or policymakers, your messages should be easy to understand, backed up by facts and statistics, and relevant to them. It is important to remember that an advocate's message should be constructive and have specific actions. Complaining without concrete ways to change or without the desire to work together to make the change is not advocacy and will not accomplish the goal of improving care.

You do not have to use fancy words or medical jargon to make a strong point. It is more important to explain why they should care and what they can do to help. Your unique voice and personal story can have a remarkable impact on decision-makers – they can even be more influential than statistics or long reports.

The method

Getting the message right is important, but it is no good if you cannot reach your intended audience! Think about how best you can introduce the issue to them, and how much time they might have. For example, a busy policymaker is unlikely to have time to read a long report on an issue they're unfamiliar with, so a short memo or infographic could be more successful at grabbing their attention.

The way in which the message is delivered can also have a substantial impact on its success in reaching the target audience. It is important to consider how easy or difficult a given method might be for you, and how effective that method could be in conveying your message. For example, a report on the TV news might be hugely influential but would be extremely difficult to achieve. Activities like writing letters and posting on social media are posting on social media are more easily achieved at the beginning.

Our mission
together is to
Detect;
Protect;
Correct!

STEP 5: WORKSHEET

Engage key individuals to support your cause

I would like my message to be:

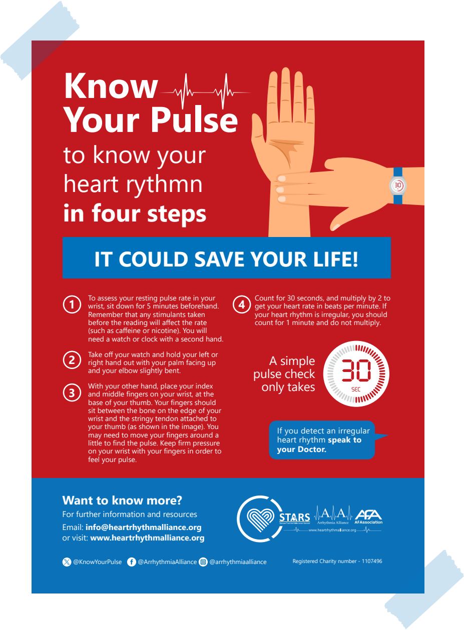
I can share my message by:

My first step to engage is:

Possible ways to engage with key people might include:

- Social media posts
- Face-to-face meetings
- Conferences or political events
- Letters
- Petitions
- Traditional media

And do not forget, simply putting up a poster in your local community centre to encourage people to ‘Know your Pulse’ represents a huge step forward! - [Know Your Pulse - YouTube]



Know Your Pulse

to know your heart rythmn **in four steps**

IT COULD SAVE YOUR LIFE!

① To assess your resting pulse rate in your wrist, sit down for 5 minutes beforehand. Remember that any stimulants taken before the reading will affect the rate (such as caffeine or nicotine). You will need a watch or clock with a second hand.

② Take off your watch and hold your left or right hand out with your palm facing up and your elbow slightly bent.

③ With your other hand, place your index and middle fingers on your wrist, at the base of your thumb. Your fingers should sit between the bone on the edge of your wrist and the stringy tendon attached to your thumb (as shown in the image). You may need to move your fingers around a little to find the pulse. Keep firm pressure on your wrist with your fingers in order to feel your pulse.

④ Count for 30 seconds, and multiply by 2 to get your heart rate in beats per minute. If your heart rhythm is irregular, you should count for 1 minute and do not multiply.

A simple pulse check only takes 30 SEC

If you detect an irregular heart rhythm **speak to your Doctor.**

Want to know more?

For further information and resources

Email: **info@heartrhythmalliance.org**

or visit: **www.heartrhythmalliance.org**

@KnowYourPulse @ArrhythmiaAlliance @arrhythmiaalliance

Registered Charity number - 1107496

Congratulations!

You have successfully completed the worksheet portion of your training. We look forward to working together on the next stage of training with you to refine your skills and get you engaged.

For more information on our advocacy program or for further resources and additional links, please click here.

Arrhythmia Alliance Advocacy enquiries
a.baer@heartrhythmalliance.org

Arrhythmia Alliance General enquiries
+1 843 415 1886
info-us@heartrhythmalliance.org

Media enquiries
adminteam@heartrhythmalliance.org

Arrhythmia Alliance
www.heartrhythmalliance.org