European Heart Network
Fighting heart disease and stroke

Empowering patients with cardiovascular disease through advocacy: A comprehensive guide

The "EHN Patients Advocacy Handbook," developed by the European Heart Network (EHN), empowers individuals with cardiovascular disease (CVD) by providing essential advocacy skills and resources.

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Introduction

The importance of patient advocacy in cardiovascular health

Advocacy plays a crucial role in shaping policies and legislation, promoting awareness, and driving change in cardiovascular health. The voices and agency of patients living with cardiovascular disease (CVD) are powerful in influencing researchers, funding entities, decision-makers, such as policymakers and legislators, and service provides to prioritize initiatives that improve access to quality care, enhance research opportunities and implement preventive measures. Engaging people with lived experience in advocacy efforts, helps them to empower themselves but also to contribute to the collective effort of advancing cardiovascular health for individuals and communities worldwide.

Purpose and scope of the handbook

The purpose of this handbook is to help CVD patients living with CVD with the knowledge, skills, resources, and a practical guidance needed to effectively advocate for their rights, access to quality care, and the development of policies that address the challenges around CVD. This handbook aims to help individuals to actively participate in shaping policies, influence decision-makers, and drive positive change in cardiovascular health. The scope of this handbook is engaging with policymakers but could also be applied to other audiences.

Patient advocacy is crucial for improving healthcare outcomes as it ensures that the voices, needs, and concerns of patients are heard and addressed in healthcare decision-making processes. By advocating for themselves and others, patients can drive positive change in healthcare policies, practices, and systems. Patient advocacy helps to promote patient-centred care, in which individuals are active participants in their own healthcare journey, leading to better treatment adherence, improved communication between patients and healthcare providers, and ultimately, enhanced health outcomes.

Definition of advocacy and its role in healthcare policy

Advocacy means public support of an idea, plan, or way to do something[1]. Advocacy includes actions intended to influence selected people, governments, private companies or other institutions in order to achieve a desired policy, practice, social, or political change that will benefit particular groups.

Advocacy in healthcare involves actively supporting and promoting policies, programmes, practices research topics designed to enhance the quality, accessibility, and equity of healthcare services for individuals and communities.

[1] https://dictionary.cambridge.org/dictionary/english/advocacy

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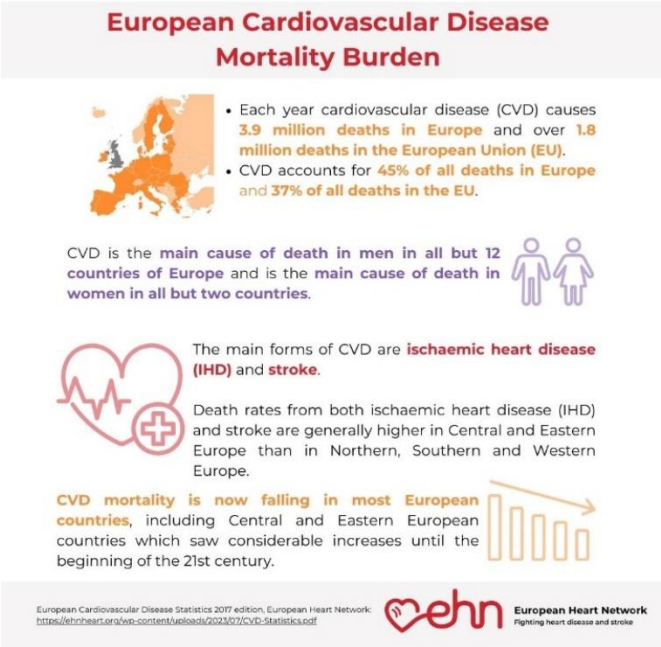
At its core, advocacy translates the patient experiences and needs into tangible health policy reforms, legislative actions focusing on person centred care.

Part 1: Understanding Cardiovascular Disease (CVD)

Key Facts around Cardiovascular Disease

Mortality of CVD in Europe:

- CVD is the leading cause of death in the wider Europe[2] causing 3.9 million deaths every year, 45% of all deaths. In the EU, CVD is also the leading cause of death accounting for over 1.8 million deaths every year, which corresponds to 37% of all deaths. 1.8 MILLION people equals the population of Vienna, Barcelona, Warsaw, Budapest, Milan or Hamburg, and represents about 5000 deaths per day in the EU.[3]
- Ischemic heart disease (IHD) is the leading single cause of premature mortality under 65 in both men (248,000 deaths, 16%) and women (76,121 deaths, 11%).[4]
- In 2019, the burden of CVD was also reflected in the number of Disability-Adjusted Life Years (DALYs), which totalled 27,729,997.77, representing 19.50% of the total DALYs and a DALY rate of 6,197.52 per 100,000 people. For Europe as a whole, the number of DALYs for CVD was at 67.5 million, making up 24% of the total DALYs in Europe.
- The main forms of CVD are Coronary Heart Disease and Stroke.



[2] https://ehnheart.org/wp-content/uploads/2023/07/CVD-Statistics.pdf

[3] https://ehnheart.org/wp-content/uploads/2023/08/CVD-Plan-digital-edition.pdf

[4] https://ehnheart.org/wp-content/uploads/2023/07/CVD-Statistics.pdf

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Prevalence of CVD:

- Each year in the European Union, over 6 million new cases of cardiovascular diseases are diagnosed, and more than 1.8 million people die from them.
- CVD is the leading cause of mortality under 65 years in Europe, accounting for around 667,000 deaths (29% of all deaths under 65) each year. Among men, CVD is the most common cause of death under 65, responsible for around 479,000 deaths (31%), while in women, it is the second largest cause of death, with 188,000 deaths (26%).[5]

Risk Factors:

- Hypertension is a key biological risk factor for CVD but often goes undetected, untreated or uncontrolled. CVD is also a major cause of disability and reduced quality of life, impacting the lives of some 60 million people who live with CVD in the European Union[6].
- Cholesterol is another critical biological risk factor for cardiovascular disease (CVD) that can often go undetected, untreated, or poorly managed. Elevated levels of LDL cholesterol, commonly known as "bad" cholesterol, can lead to the buildup of plaques in the arteries, increasing the risk of heart attack and stroke.

Inequalities and CVD:

- The highest standardised death rates for cerebrovascular diseases are recorded in Bulgaria, Latvia, Romania and Lithuania. By contrast, the lowest rates are recorded in France, Ireland and Luxembourg. The burden of CVD varies across European countries, with higher mortality rates in Central and Eastern Europe compared to other regions[7].
- Over three quarters of CVD deaths take place in low- and middle-income countries[8]
- Inequalities in mortality from CVD account for almost half of the excess mortality in lower socio-economic groups in most European countries[9].

[5] https://ehnheart.org/wp-content/uploads/2023/07/CVD-Statistics.pdf

[6] https://www.escardio.org/static-file/Escardio/Advocacy/Documents/EHHC-Brochure-2023.pdf

[7] https://ec.europa.eu/eurostat/statistics-explained/index.php?title=Cardiovascular_diseases_statistics#Deaths_from_cardiovascular_diseases

[8] https://www.who.int/news-room/fact-sheets/detail/cardiovascular-diseases-(cvds)

[9] https://ehnheart.org/wp-content/uploads/2023/08/CVD-Plan-digital-edition.pdf

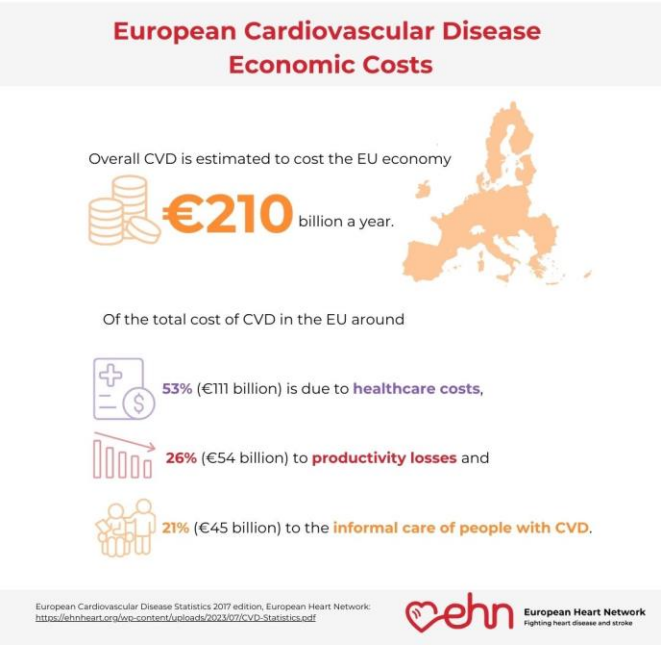
- CVD in Europe, accounts for 45% and 39% of fatalities in women and men respectively[10].
- Although often misunderstood as a "men's disease," CVD is the top cause of death among women in the WHO European Region. Stroke affects not just older women, but also accounts for 8.2% of maternal deaths annually. Heart attacks in women account for one third of all women deaths and have worse outcomes and higher mortality rates than men. Women are less likely to receive evidence-based treatments for cardiovascular conditions, and when they do, they are more likely to experience delays.

  The risk of mortality following a heart attack is 20% greater in women compared to men.

  These gender inequalities are also present in the development of new treatments for CVD, where less than 27% of participants in clinical trial for new treatments for CVD in the EU are women[11].

Economic burden of CVD:

In 2017, the annual cost of cardiovascular diseases in the EU amounts to €210 billion, including €111 billion in healthcare costs, €54 billion in productivity losses, and €45 billion in informal care costs[12].



[10] https://ehnheart.org/wp-content/uploads/2023/07/CVD-Statistics.pdf

[11] https://ehnheart.org/wp-content/uploads/2023/08/CVD-Plan-digital-edition.pdf

[12] https://ehnheart.org/wp-content/uploads/2023/07/CVD-Statistics.pdf

Part 2: Advocacy Opportunities

2.1 How and where patients can best advocate for better CVD treatment and care

At the local and regional level:

- Local and regional politicians: Engage with city council members, mayors, and regional representatives to advocate for improved access to CVD treatments and healthcare services.
- Local health fairs, conferences and seminars: Attend and participate in local health events to raise awareness about CVD issues and advocate for better treatment and care options.
- Engage with health organisations and get involved with their activities in your region, e.g. spread their message to local newspapers, link them with local healthcare professionals, etc.

At national level:

- National politicians: Communicate with members of parliament, congress or national health ministries about the importance of prioritizing CVD research, funding, and healthcare policies.
- National health fairs, conferences and seminars: Utilise national platforms to advocate for increased funding for CVD research and better healthcare infrastructure.

At European level:

- In the European Parliament, plenaries, at Committee sessions (in particular Members of the SANT Subcommittee which is focusing exclusively on health topics.): Engage with Members of the European Parliament (MEPs) from your country , during legislative sessions to promote EU-wide policies supporting CVD prevention and treatment. Ask your national health organisation if they have templates you could use.
- At events attended by MEPs: Participate in events where MEPs are present to advocate for cross-border collaboration on CVD research and healthcare initiatives. Take the opportunity to tell your own story, to illustrate the human impact of CVD and the importance of policy change.
- European health fairs, conferences and seminars: Network with healthcare professionals and policymakers across Europe to advocate for harmonized standards of care for CVD patients.

Important Organisations at EU level with which EHN works:

- European Patients' Forum

- European Medicines Agency

2.2 When to Advocate

Advocacy efforts can be strategically timed to coincide with key dates and events, both at the European and national, regional, and local levels.

European Level:

At the European level, engaging with Members of the European Parliament (MEPs) during committee meetings and plenary sessions can be highly effective. Additionally, aligning advocacy efforts with significant events, awareness days and months, and campaigns can amplify impact. For example:

- Every February, **Heart Month** serves as an opportune time to raise awareness about heart disease across Europe.
- February 14th - **Valentine's Day**
- March 8th - **International Women's Day**
- March 14th – **European Day for Prevention of Cardiovascular Risk**
- March 24th - **World Tuberculosis Day**
- 29 April to 5 May 2025 (TBC) - **Heart Failure Awareness Days 2025**
- May – **International Hypertension Month**
- May 31st - **World No Tobacco Day**
- September 29th - **World Heart Day**
- October - **Obesity Awareness Month**
- October 29th - **World Stroke Day**
- November - **Diabetes Awareness Month**
- November - **European Health and Wellbeing Week**
- November 14th - **World Diabetes Day**

Tip! Dates mentioned above for International/European level, also apply at national, regional and local levels to advocate for cardiovascular health.

National, Regional, and Local Levels:

Similar advocacy efforts can be tailored to national, regional, and local contexts, leveraging pertinent dates and occasions to maximize outreach and impact. This may include:

- Partnering with local health authorities and organizations to host awareness events or workshops. Share your personal story to convey the human impact of CVD in every day life, , backed by evidence and a clear policy ask.

- Collaborating with educational institutions to integrate health education modules into curricula.
- Engaging with community leaders and stakeholders to advocate for policy changes or initiatives that promote cardiovascular health. Many organisations have departments that deal with patient's rights and advocacy. Contact them for collaboration.

Here is a list of European countries with specific dates on Cardiovascular Health:

- **France** - Fédération Française de Cardiologie (French Federation of Cardiology): The French Federation of Cardiology organizes events like the "Semaine du Cœur" (Heart Week) in September, which includes activities aimed at promoting heart health and preventing cardiovascular diseases.
- **Germany** - Deutsche Herzstiftung (German Heart Foundation): The German Heart Foundation conducts campaigns such as "Herzwochen" (Heart Weeks) in November, dedicated to raising awareness about cardiovascular diseases and prevention strategies.
- **Italy** - Fondazione Italiana per il Cuore (Italian Heart Foundation): The Italian Heart Foundation organizes initiatives like "Settimana del Cuore" (Heart Week) in October, dedicated to promoting cardiovascular health and prevention measures.
- **Netherlands** - Hartstichting (Dutch Heart Foundation): The Dutch Heart Foundation hosts events such as "Nationale Hartweek" (National Heart Week) in April, which includes activities aimed at raising awareness about heart health and fundraising for cardiovascular research.
- **Spain** - Fundación Española del Corazón (Spanish Heart Foundation): The Spanish Heart Foundation conducts campaigns such as "Semana del Corazón" (Heart Week) in late September or early October, focusing on raising awareness about heart health and healthy lifestyle choices.
- **Sweden** - Hjärt-Lungfonden (Swedish Heart-Lung Foundation): The Swedish Heart-Lung Foundation conducts campaigns like "Hjärtveckan" (Heart Week) in April, focusing on raising awareness about heart diseases and prevention strategies. There is also the Heart month (Hjärtemånaden) in February every year. With Heart Month, the Swedish Heart and Lung Association aims to increase the knowledge about the heart and blood vessels and their diseases. The Swedish Heart and Lung Association also conducts "HLR-veckan", a CPR week every year in October to raise awareness of how important it is for everyone in society to learn cardiopulmonary resuscitation.
- **United Kingdom** - British Heart Foundation (BHF): The British Heart Foundation organizes various campaigns throughout the year, including Heart Month in February and "Wear It. Beat It". day in June, focusing on raising awareness about heart health and fundraising for cardiovascular research.

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Part 3: Effective Advocacy Strategies

Please find here some tips and advice for effective communication with policymakers, including how to articulate personal experiences and concerns:

3.1 Find your Representative(s): Get to know your legislators

Find your representatives. Map the stakeholders who work on health and healthcare in the municipality, the region, national or at European level.

Understanding the priorities and advocacy channels can of your representatives can help tailor your messaging to align with regional healthcare agendas. Map out their affiliations, legislative priorities, and key stakeholders can guide your advocacy strategies.

European Representatives: For advocacy efforts spanning beyond national borders, it's essential to engage with European Parliament members (MEPs) and r EU officials who influence healthcare policies at the European level. Researching their committee assignments, policy interests, and participation in cardiovascular health initiatives can inform targeted advocacy campaigns within the European Union.

Mapping exercise

Before you communicate with those you hope to influence, try to identify:

What are their current interests and priorities? Do they have a role in committees that oversee health policy? What are their positions? Where do they stand on the issue/problem and on the solutions you are proposing? What aspects of your proposal are they likely to question? What will motivate them to support your proposal? How could they benefit from your proposal? Are they facing an election this year?

Tip! You can also check on their personal history: Do you have anything in common? If you cannot identify the right person, contact your mayor, local MP or MEP and them to link you with their relevant colleagues. .

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3.2 Target your message to the specific person/organisation you are trying to influence

Don't underestimate your own power as an advocate.

Ask to yourself: Why should they listen to you? Your power comes from the legitimacy you hold in the eyes of the person you are trying to influence.

- **Expertise and knowledge-based legitimacy**: Developed through your lived experience as a patient or a care giver and your work on a given issue and/or the research you have published.
- **People-based legitimacy:** Gained through working with other people affected by a given issue.
- **Cause-based legitimacy:** your legitimacy may come from a cause or mission which is universally revered – for example, the right to life (article 2 of the Charter of Fundamental Rights of the European Union[13] and the European Convention on Human Rights[14]).

Tip! Prior to an advocacy meeting with someone you are seeking to influence, practise introducing yourself in 20 seconds in a way that establishes your power and legitimacy. Practise answering the question: Who are you and why should I listen to you?

3.3 Introduce yourself and your organisation via email, virtual meeting, call or in-person meeting

After finding their email or phone number, make an initial approach and send them a message to introduce yourself/your organisation.

Tailor your advocacy message to your target audience! This will depend on the person or institution you are trying to influence. The language and the detail you use will likewise depend on to whom you are communicating your advocacy message. If you are communicating it to the general public, or in the media, you will need to keep the message short and relatable, with a key statistic or fact If you are communicating the message to a civil servant in a private meeting, you can go into more detail and provide more evidence.

[13] https://fra.europa.eu/en/eu-charter/article/2-right-life
[14] https://www.echr.coe.int/documents/d/echr/convention_ENG

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Tip! Try to put yourself in the shoes of the policy maker, even if you don't support or agree with all of their views. What is on his/her agenda? What will make him/her listen to you? That way, you can tailor your message and your engagement with them to where they are at and refer to things you know they care about. Try to focus on common interests and values you share with them.

3.4 What should an advocacy message contain?

An advocacy message must capture:

- The problem and evidence of the negative impact of this problem.
- The workable solution(s) and how this will bring positive change
- The specific action you want your target audience to take

Analyse and research the problem you want to address so that you are clear about the root causes of the problem and the barriers to/opportunities for change.

Understand the steps needed to secure a long-term goal.

Have a clear "ask" – a specific action you will request from the policymaker, such as voting for a particular piece of legislation. Be prepared to answer questions and to listen to your policymaker's perspectives on the issue.

Have ready a razor-sharp message to convey your message quickly (in less than a minute). Include: What is the problem and how can change be achieved? What do you want from the person you're speaking with? It could simply be an opportunity to meet again more formally together with other policymakers and discuss further in detail.

Tip! Pick your "ask". It is better to focus each meeting on one issue than to bombard them with multiple requests.

Do not hesitate to meet with staff if the elected official is unavailable. Practise your talking points, show up 10 minutes early and be understanding if the legislator or staff are late.

3.5 Follow up of a meeting or campaign.

Leave them brief information on your organisation and the issues you are discussing. One-pagers with bullet points are best – staff do not have time to peruse long handouts.

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After the meeting always send a brief thank you within a day or two of your meeting, summarising what has been agreed. Refer to Meeting Follow Up for a helpful template. In the same email, offer to answer any additional questions. Send the documents you provided during the meeting if you were not able to send them before the meeting. Share the pictures you took!

Tip! Ask in writing if you are able to share a picture or short note on your meeting in social media: This will help to amplify your message, and typically, policy makers appreciate this publicity .

Part 4: Communication, presentation skills

Tweet patterns: Create engaging tweet templates that highlight key messages and calls to action. Include relevant hashtags and mentions to amplify reach.

- Schedule tweets during peak times when your audience is most active to maximise visibility and engagement. Help generate positive media attention when legislators visit your organisation by working with their staff to develop and submit a press release with photos.

Press Releases: Collaborate with legislators' staff to draft and submit press releases when they visit your organisation. Include high-quality photos to attract media interest.

- Media Outreach: Contact local journalists and media outlets in advance to inform them of the visit and its significance.

  Write a letter to the editor of your local newspaper mentioning your legislator when they support or otherwise advances your issues in the Congress.

When your legislator supports or advances your issues in Parliament, write a letter to the editor of your local newspaper. Highlight their contributions and express your gratitude.

Publication Tips: Keep letters concise and focused. Follow the newspaper's submission guidelines for format and length. Personalise the letter to reflect the local impact of the legislator's actions.

- Follow and interact with your legislators on social media. Visit their official pages to see your legislator's X (Twitter) and Facebook.

Stay updated on your legislators' activities by following them on Twitter, Facebook, and other social media platforms.

Interactive Engagement: Like, share, and comment on your legislators' posts to increase visibility and build a rapport. Tag them in your posts related to advocacy efforts to draw their attention.

Content Creation: Create compelling content, such as infographics and short videos, that legislators are likely to share.

Part 5: Advocacy Tools and Resources

- **Sample advocacy letters and emails for meetings with policymakers.**

Below is an example of emails used in the past for reaching out to MEPs for the EACH Summit 10-13 December 2023:

Dear MEP Olekas,

As the European Heart Network, we are writing to request a meeting with you during the week of December 11th to discuss the biggest killer in Europe. (Lithuania Stats)

From 11-14th an exhibition dedicated to cardiovascular health will take place in the European Parliament in Strasbourg in the Swan area. and we would love to see you there.

We believe that policy makers should not need to choose between electability and taking action on what is demonstrably the biggest threat to public health in the EU today.

We, as leaders of the European Alliance for Cardiovascular Health, representing scientific societies, patient organisations, industries and foundations are coordinating our social media and media activities to ensure that those MEPs who make serious commitments to CVD reach as many people as possible at a local level. For our organisation, we are pushing for an EU Cardiovascular Health Plan because it can provide a much needed policy framework for action.

If you look to tackle a major public health issue for your manifestos, then look no further than the biggest killer in the EU and worldwide. If you look to tackle gender imbalances, take note that today more women than men will die of CVD and yet it is still treated as a "men's disease". If you are concerned about disparities between east and west, it is important to note that you have a 70% chance in Bulgaria of dying of CVD today compared with 24% in Denmark.

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Action to promote cardiovascular health is the fight for gender, generational and geographical equity. It is the fight against ageism and structural inequalities.
It is the means to enable a silver economy and keep our systems sustainable. It is the public health campaign of this generation.

Would you have 30 minutes during Strasbourg to come down to meet with us to discuss the impact of cardiovascular disease in our country and if you are willing, have a short interview?

If you would like to discuss this, we are more than happy to set up a short call.

Thank you for your time and we look forward to hearing from you.

Best regards,

- **Templates for creating advocacy materials such as fact sheets or infographics.**

EACH Factsheet 1 CVD general overview

EACH Factsheet 2 Geographical inequalities

EACH Factsheet 3 Gender Inequalities

EACH Factsheet 4 Burden of Disease

EACH Factsheet 5 Stroke

EACH Factsheet 6 Chronic Kidney Disease

- **List of relevant websites, organisations, and resources for further information and support.**

List of MEPs https://www.europarl.europa.eu/meps/en/search/advanced

- **Additional resources, such as relevant research studies or policy documents.**

EHN CVD Statistics 2017

EHN-ESC Blueprint for EU Action

- **Testimonials or success stories from patients who have engaged in advocacy efforts.**

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For more information or support , please contact EHN Policy Advisor Patients & Research Carlos Altuna (caltuna@ehnheart.org)