

Time to DeLiver: advocacy toolkit



This toolkit has been developed to help ELPA members make effective use of the materials developed as part of the **Time To DeLiver** campaign.

The toolkit provides a number of **practical tips** to help ELPA members work with key stakeholders in their countries, including policymakers, healthcare professionals, patients and the public.

Advocacy is an important part of introducing change in policy, practice, public opinion, and public health priorities

ELPA's ambition is to improve the treatment and management of people with hepatic encephalopathy (HE)

This advocacy toolkit is designed to help ELPA members:

- Raise awareness of HE** advanced liver disease and its impact on patients, health services and economies in Europe
- Dispel myths about HE** and highlight why not enough attention is currently focused on HE
- Recommend ways of improving the **treatment and management of HE** through working with healthcare professionals
- Help people with HE**, their carers and their families understand more about the condition

Time To DeLiver: advocacy materials



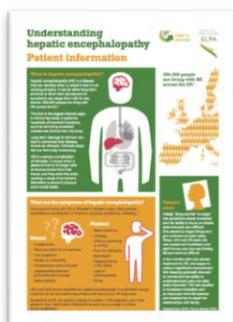
As part of its Time to DeLiver campaign, ELPA has produced a number of resources to help your local advocacy work.

These materials include:



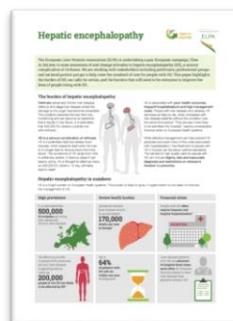
Time to DeLiver Report

- To be shared with politicians, decision-makers and clinicians
- Explains what HE is, its signs and symptoms
- Includes case studies, describing the human impact of HE
- Highlights ten calls to action, aimed at improving the identification, treatment and management of HE



Understanding HE patient leaflet

- To be shared with HE patients, their carers and families
- Provides information about HE, its symptoms and treatment
- Contains the contact details of local patient groups



HE factsheet

- To be shared with politicians, decision-makers and clinicians
- Explains what HE is and the burden across Europe
- Outlines the different way stakeholders can do their bit to improve HE outcomes

How to use these materials

- Target key audiences with appropriate materials
- Distribute these materials in both print and online formats
- Use social media to promote these resources
- Hold meetings such as coffee mornings, workshops and roundtables



Contact politicians and decision-makers



Politicians, government officials and other decision-makers have the power to make the big changes that will benefit many patients with HE.

Who should I contact?

- Approach local, national or EU-level politicians
- This includes your local politician and/or Member of the European Parliament (MEP)
- Identify the people or groups with an interest in health issues - e.g. Health Ministry Officials, public health bodies or health system managers

How to connect

- Send a letter or email – tips for writing an engaging email can be found in this toolkit
- Send them copies of the ELPA materials – especially the **Time to DeLiver Report** and **HE factsheet**
- Direct tweet or tag them in a Facebook post
- Invite them to attend a roundtable or workshop on HE



Call on politicians and decision-makers to act on HE

- ✓ Ask for their assistance to **improve standards of care** for managing HE
- ✓ Ask them to make **resources available** so that doctors are trained to properly manage HE patients

Contact healthcare professionals



Healthcare professionals are the people directly responsible for the treatment and management of patients with HE.

They have the power to improve the health outcomes of the patients they treat, and are critical in improving patient pathways and standards of care.

Who should I contact?

- Professional organisations: the groups that represent or regulate healthcare professionals
- Frontline staff: the doctors and nurses that treat patients

How to connect

- Send a letter or email
- Send your healthcare professional a copy of the ELPA materials
- Ask the clinic or facility if you can leave copies of the ELPA materials in their clinic
- Invite them to attend a roundtable or a coffee morning



Call on healthcare professionals to act on HE:

- ✓ Ask them to develop simplified guidelines that outline best practice care and support for people with HE
- ✓ Ask them about their own understanding of HE – ensure your healthcare professional is confident identifying the signs and symptoms of HE
- ✓ Ask them to provide HE patients – and their carers – with easy-to-interpret information about HE



People with HE and those that care for them may not have all the information available to them to understand their condition and the best ways of managing it.

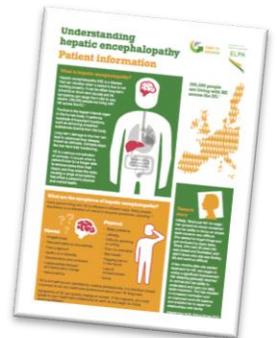
ELPA's materials have been designed to help those affected by HE better understand the condition and empower them to ask for better care.

Who should I contact?

- People with HE or those at risk of HE, such as people with advanced liver disease
- Those who care for people with HE or advanced liver disease
- Other local patient groups or charities

How to connect

- Connect on Facebook or Twitter
- Provide copies of **Understanding HE leaflet** to the local liver clinic for distribution to patients
- Host a coffee morning to bring people together



Ways to connect with people with HE or their carers:

- ✓ Develop patient information of your own – use the ELPA materials as a source of inspiration!
- ✓ Develop a survey to better identify what local support patients and carers could benefit from

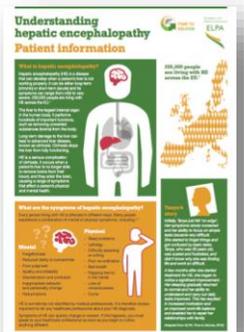
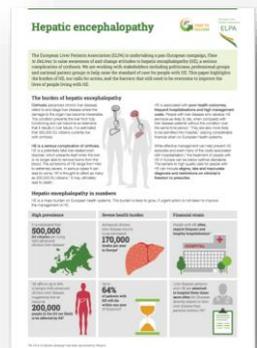
How to write a powerful email or letter ELPA



Writing a letter or email is an easy way to connect with a range of stakeholders – politicians, government officials, decision-makers, or healthcare professionals.

Here's how to make sure your letter or email has maximum impact are outlined below:

1. Be sure to explain what HE is, how it is diagnosed and treated
(All of this information can be found in the **Understanding HE leaflet**)
2. Include key facts and figures about HE – this will particularly appeal to politicians, government officials and decision-makers
(For facts and figures take a look at the **HE factsheet**)
3. Offer a solution – let the person you're writing to know what they can do to help people with HE (The ways that different stakeholders can help are outlined in the **HE factsheet**)
4. Consider including case studies - personal stories and testimonials can provide powerful examples of the messages you are trying to communicate
(A number of case studies are in the **Time to DeLiver Report** – feel free to include these)
5. Keep your note short and simple – no more than one side of paper (approximately 350-400 words)
6. Include your contact details (address and email) and provide link to your website and Facebook or LinkedIn page
7. Follow up – if you haven't received a response send a reminder note or email
8. Don't forget to include a copy of the ELPA materials with your letter or email



Connect, flag and tag using social media



Social media will help you raise awareness of HE, generate interest and connect with patients, carers and decision-makers

You can also use social media to direct people to the ELPA materials, case studies and alert them to events!

Details of some of the major social media platforms – and how to use them – are outlined below

Set up a **Facebook** page – this will allow you to connect with patients, carers and other patient groups.



- Use Facebook to share information on your organisation and key facts about HE. You can also use Facebook to invite people to events and promote your website
- Encourage Facebook friends to “share” and “like” your posts
- Tag friends in posts to spread your messages more widely
- For more tips on creating and refining your Facebook account: <https://www.facebook.com/business>

Use **Twitter** to alert people to events, new data and resources.



- Messages must be no longer than 140 characters
- Include hashtags (#) before words so your information comes up when people search that word, e.g #understandingHE
- Retweet relevant news from other organisations and associations to show your group is active in this area
- Direct tweet politicians and/or decision-makers links to yours and ELPA’s resources and events
- Links to websites can be shortened using Bitly: <https://bitly.com>

Wikipedia is a free online information source, that’s trusted by patients and physicians and available in multiple languages.

- Patients, carers and decision makers will all use Wikipedia to learn more about HE
- Edit the Wikipedia page and link to your website and share key data about HE
- To learn more about editing Wikipedia: http://en.wikipedia.org/wiki/Wikipedia:About#Contributing_to_Wikipedia

YouTube is a great way for sharing videos, such as patient testimonials or tutorials for patients and their carers.



- Create an account and upload videos to connect with people!
- For more tips: <https://www.youtube.com/user/nonprofits>

LinkedIn is a useful platform for sharing information and for connecting with volunteers, healthcare professionals and other patient groups.



- Create a LinkedIn page and use it to post status updates, share news, connect volunteers and grow your community
- “Follow” other patient groups
- More information on how to use LinkedIn can be found here: <http://nonprofits.linkedin.com>



Holding a meeting



Meetings are a great way of bringing together people to talk about HE and what can be done to improve patient outcomes.

If you haven't ever held an event, use this list to guide your planning:

- 1. Decide on a meeting format**
 - Informal meeting?
 - Formal meeting?
 - One-to-one meeting?
- 2. Pull together an invitee list**
 - Before sending out invites, draw up a list of the best people to invite to your event
- 3. Send out the invitations**
 - The invite should contain logistical information: time, date, venue
 - The invite should also clearly outline the purpose of the event and desired outcomes
- 4. Develop an agenda**
 - This will make it clear to you – and the attendees – the purpose of the event and its intended outcomes
- 5. Develop talking points**
 - Write down all the key points you want to make – this will make it clear to you what you need to say on the day
 - Keep your messages simple and engaging
- 6. Follow up with attendees**
 - Send attendees a note thanking them for attending the event
 - In your note, include "actions" outlining the ways that attendees can help to improve the treatment and management of HE

Types of meeting

Informal meetings

- This might include a coffee morning that brings together patients and their carers
- Use this as an opportunity to swap notes about local services - both the good and the bad aspects of services

Formal meeting

- This is likely to be a more structured event – such as a workshop or a roundtable
- This style of meeting is a good way of discussing services with doctors, decision makers or other patient groups
- Policy roundtables often serve to slowly shape the priorities of decision makers

Don't want to hold your own event

- Consider attending an existing event or conference that already has a high profile or which will be attended by the people you want to connect with
- An example might be the International Liver Congress organised by EASL

