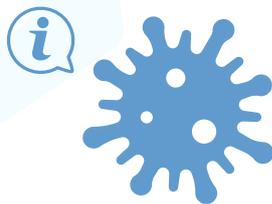


COVID-19 Toolkit for liver patient associations

The COVID-19 pandemic is challenging for everyone in Europe. Information about the virus is limited and treatment of other diseases has been impacted. This puts liver patients in a difficult position.

This toolkit has been developed to help liver disease patients during the COVID-19 pandemic. The goal of the toolkit is to help patient associations to support their patients during this time. Three different sections have been made: each section has its own goal.



Section 1 helps patient associations to communicate accurate information about COVID-19 to patients



Section 2 advises on the use of social media and newsletters to make communication to patients easier



Section 3 gives tips about how advocacy can be used to improve the situation and treatment of liver disease patients.

We encourage you to use this toolkit to help your patients and to improve the treatment they receive. This document has been made by José Willemse and Martine Walmsley, patient advocates, in collaboration with [RPP](#) and endorsed by [ERN Rare Liver](#) and [EASL](#), as part of the RPP Patient Grant scheme.

Care of Patients with Liver Disease during the COVID-19 Pandemic

The European Association for the Study of the Liver (EASL) and the European Society of Clinical Microbiology and Infectious Diseases (ESCMID) published a Position Paper on the 'Care of patients with liver disease during the COVID-19 pandemic' to help healthcare providers when reallocating resources to manage the care of people with liver disease and those who have had liver transplants. The world is still learning about the impact of SARS-CoV-2 (the virus that causes COVID-19) on liver diseases, and until we have evidence to guide decisions about care, this expert opinion is important. This document is a lay summary of the guidance in the EASL-ESCMID Position Paper and is intended to be read alongside local and national guidance about COVID-19.

The lay summary covers:

- How healthcare providers are minimising COVID-19 transmission
- What changes to expect in your care during the pandemic
- What to expect if you get COVID-19
- Prioritisation of patients for some tests and procedures

Minimising the risk of COVID-19 transmission

During the COVID-19 pandemic, healthcare providers may need to reorganise *where* and *how* care is provided by reducing your physical contact with your medical team in hospital. This is to minimise the risk of your exposure to SARS-CoV-2.

You may find that hospitals arrange waiting areas differently and put new systems in place to help protect you from the virus. Where it is possible, and if hospitals have the right resources, you may even have some appointments by phone or video.

In some cases, your General Practitioner (GP) or local hospital will work with your hospital specialist to take over some of your care and monitoring, and you may be asked to go to a different hospital than usual. Clear communication is critical between specialist centres, local healthcare providers, general practitioners and patients for this to work well.

What to expect during the COVID-19 pandemic

People who have liver disease

Doctors must balance the risks of harmful infection of the virus against the risks and benefits of delaying or changing your care.

Expect:

- some routine appointments and tests to be rearranged for a later date (including some cancer monitoring and varices screening);
- non-invasive tests might be used to assess your risk for varices (veins in your gullet).

If you have liver cancer or advanced liver disease (decompensated cirrhosis) with complications such as jaundice, hepatic encephalopathy, ascites, or variceal bleeding, expect:

- the usual guidelines to be followed for your care but with minimal face-to-face care;
- the most urgent cases to be prioritised for liver transplantation and any in-hospital assessments to be kept to a minimum;
- an emphasis on the importance of vaccinations for *Streptococcus pneumoniae* and influenza;
- an emphasis on reducing the risk of spontaneous bacterial peritonitis and hepatic encephalopathy;
- to be tested for SARS-CoV-2 if you develop serious liver complications;
- to be admitted to hospital early if you have COVID-19.

Special situations

Viral hepatitis

Viral hepatitis is not thought to increase the risk of severe COVID-19. However, expect your doctor to send your ongoing antiviral prescriptions by mail.

NAFLD/NASH

If you have fatty liver disease (NAFLD) or NASH, your doctor will take into account additional risks that you may have, including diabetes, hypertension and obesity.

Autoimmune liver disease

If you take medicine for autoimmune liver disease, it is important *not* to reduce your dose. Your specialist will only consider this under some circumstances. It is also important to have vaccinations for *Streptococcus pneumoniae* and influenza.

People waiting for a liver transplant

Expect:

- to be tested for SARS-CoV-2 just before the transplant operation (as well as testing of the donor liver);
- to be told about the additional risks associated with COVID-19 and transplantation;
- to give your consent to liver transplantation and the potential in-hospital risk of COVID-19 infection;
- living donor liver transplants to be considered on a case-by-case basis.

People who have had a liver transplant

Expect:

- the usual guidelines to be followed for your care and medications (including the dose of your immunosuppressant medicine) but with minimal face-to-face care;
- an emphasis on importance of vaccinations for *Streptococcus pneumoniae* and influenza;
- routine tests to be handled by your GP if your condition is stable.

What to expect if you get COVID-19

Care in hospital

Expect to be admitted into hospital if you are at higher risk of a more severe COVID-19 course. Older age, having hypertension, diabetes or obesity increase the risk. It is suspected, but not certain, that the presence of cirrhosis, liver cancer or having had a liver transplant increases the risk of catching the infection and/or having a more severe COVID-19 course.

Treatment considerations

- Antiviral drugs are being tested to treat COVID-19. There is already scientific understanding about how some of these drugs work and how they might affect people with liver disease or people who have had a liver transplant. The EASL–ESCMID Paper suggest that doctors consider including liver disease patients in early antiviral experimental treatment programmes for COVID-19.
- It is important to prevent paracetamol (acetaminophen) overdosing.
- Non-steroidal anti-inflammatory drugs (NSAIDs) are not suitable for people with cirrhosis or portal hypertension.
- The EASL–ESCMID Paper advises that treatment for cirrhosis-associated complications such as portal hypertension, ascites, hepatic encephalopathy, and spontaneous bacterial peritonitis should be continued.
- Some treatments for liver cancer may be temporarily withdrawn while you have COVID-19.
- In patients who have COVID-19 and have had a liver transplant, the doses of some of your usual medicines may be temporarily reduced if you are given antiviral therapy for COVID-19.

Tests and Procedures

Some tests and procedures for liver patients may be delayed depending on resources at your hospital, the COVID-19 risk, and your individual circumstances. The following chart shows how your doctor may prioritise this care:

| Tests and Procedures | Liver Patients without COVID-19 | Liver Patients with COVID-19 |
|---|--|---|
| Esophagogastroduodenoscopy (EGD) for variceal screening | Patients at highest risk of a bleed may be prioritised. | These procedures should be limited to emergencies: |
| Therapeutic endoscopic retrograde cholangiography (ERC) | Dilatation or stent replacement should be performed for people who have had a liver transplant or who have primary sclerosing cholangitis, but individual risk–benefit should be considered carefully. | <ul style="list-style-type: none"> gastrointestinal bleeding bacterial cholangitis other life-threatening conditions |
| Ultrasound (liver cancer surveillance) | May be delayed. People with elevated alpha-fetoprotein levels, advanced cirrhosis, chronic hepatitis B and NASH/diabetes may be prioritised. | Should be performed after recovery from COVID-19. |
| Liver biopsy | <p>May be delayed for</p> <ul style="list-style-type: none"> biopsies to understand stage of disease for people with NAFLD and chronic viral hepatitis biopsies to diagnose disease in people with mildly raised liver blood tests <p>Cases will be prioritised where cancer is suspected and where some liver blood tests are very high without a clear reason.</p> <p>Where autoimmune liver disease is suspected, treatment may begin without a biopsy in some cases.</p> | Should be performed after recovery from COVID-19. |

Lay version written by Martine Walmsley and Maria Buti, and reviewed by ERN RARE-LIVER patient associations. Based on:

Boettler T, Newsome PN, Mondelli MU, Maticic M, Cordero E, Cornberg M, Berg T, Care of patients with liver disease during the COVID-19 pandemic: EASL-ESCMID position paper, JHEP Reports (2020), doi: <https://doi.org/10.1016/j.jhepr.2020.100113>

Effective communication during the COVID-19 pandemic

This section advises patient associations on how to use social media to reach patients and how to create messages to help patients. Social media can be an important tool to show support to patients and to share important information with them. Below you will see a step-by-step approach that identifies which topics and messages you can share with patients and who can help you to obtain relevant information.

Please use this toolkit to help your patient community!

Topics of interest to patients

- 1 Information about COVID-19
- 2 Risk of infection with COVID-19
- 3 Telemedicine
- 4 Delays in treatment
- 5 Different treatment locations

Helpful messages for patient associations to communicate to patients

- 1 Patient associations can help to provide information about COVID-19 and its consequences for patients.
- 2 Healthcare providers are taking steps to reduce the physical contact between patients and medical personnel. This will help minimise the risk of infection with COVID-19.
- 3 Appointments are increasingly conducted by phone or video. Remote health services such as monitoring, advice and education between doctors and patients can be valuable and can help reduce the risk of infection.
- 4 Certain routine appointments, such as screening and some procedures, may be postponed to a later date, when risk of infection will be lower and there is increased capacity in hospitals. In the meantime, physicians may choose alternative (non-invasive) testing methods.
- 5 With certain aspects of care and monitoring being temporarily relocated from one healthcare facility to another, patients may have appointments in different locations than usual. It is essential that specialist centres, local healthcare providers and general practitioners communicate as well as possible in order to maintain the quality of care.

Sources of information for patient associations



ERN RARE LIVER



Liver disease patient associations



EASL



Hospitals



National health institutes



Transplant organisations



Trusted physicians

Patients need your help and these messages could be helpful



- 1 Stay safe by being informed! [name organisation](#) is open for questions or a chat about what you can do to reduce the chance of contracting COVID-19!
tag your related organisations like:
@name national health institutes, @transplant organisation, @important hospitals, etc.
- 2 Dear liver patients: it is not easy to find accurate information about COVID-19 and its consequences for liver patients.
Please find reliable information here: [+link to simplified information from EASL](#)
@name national health institutes, @transplant organisation, @important hospitals, @ERN_RARE_LIVER.
- 3 Dear liver patients: [name organisation](#) is here to help you during this difficult time.
Let us know how we can assist you or what questions you have.
@name national health institutes, @transplant organisation, @important hospitals, etc.
- 4 Hospitals are changing the way they care for liver patients by reducing physical contact between patients and medical personnel. This helps to minimise the risk of #COVID19 transmission
@name national health institutes, @transplant organisation, @important hospitals, @ERN_RARE_LIVER.
- 5 Dear liver patients: Have you had an appointment by telephone yet? Telemedicine is one way to access care while respecting social distancing. Share your experience by phoning or emailing us
@your email address @name national health institutes, @transplant organisation, @important hospitals.
- 6 Dear liver patients: some procedures and treatments may be delayed during the #COVID19 pandemic, until the risk of infection is lower. At the same time, physicians may choose alternative (non-invasive) testing methods. **@name of your association @important hospitals and @important organisations related to your association.**
- 7 Dear liver patients: some of your appointments may take place in different locations than usual. Do not hesitate to ask us or your health care provider for information about this.
@name national health institutes, @transplant organisation @important hospitals, etc.

Tip: There are many websites that provide high quality pictures without copyright that you can use for your social media post, such as www.unsplash.com or www.pixabay.com

Tips for drafting a newsletter

10 tips on how to produce and use a newsletter during the COVID-19 pandemic

- 1 Develop a structure to use in every newsletter
 - If you already produce a newsletter: create a new name and keep it only for COVID-19 information. Example: Extra Newsletter 1, 2 etc.
- 2 Introduction: speak directly to your readers
 - Example: "I hope you are all doing well", "it is a difficult time for everybody"
- 3 Choose a maximum of your 5 most important items
- 4 Write content for each item
- 5 Repeat items from your last newsletter if they are important
- 6 Keep things brief! Do not write more than 100 words per item
- 7 Use links to other trusted websites as much as possible
- 8 Content:
 - update on the current situation, even when nothing has changed: no news is also news
 - repeat in every newsletter not to stop immune-suppressive medication (for those taking it)
 - links: tell people that they can trust the content of these links, like for instance: - your government COVID-19 website - social service organisations - hospitals and transplant centers - other websites important in your country or your organisation. Warn them about the 1000 websites with false/unverified information.
 - check your medical content with doctors. Ask (transplant centers) what they are telling their patients.
 - pay extra attention to:
 - general statements about COVID-19 in your country
 - general statements on COVID-19 from your doctors' organisations
 - adults with autoimmune and other rare liver diseases
 - adults with other liver diseases
 - adults with decompensates cirrhosis
 - adults who have had a transplant or are on the waiting list
 - children with liver diseases
 - ask them to contact you if they have questions or new items
- 9 End with a positive message to your members and the healthcare workers
 - examples: take care, stay strong, we'll think about you etc
 - add a nice encouraging picture to end your newsletter.
- 10 Be creative. Remember: everything that comes from your heart is never wrong and well appreciated!

ADVOCACY FOR LIVER PATIENT ASSOCIATIONS DURING AND AFTER COVID-19

If you would like to improve the way patients with liver disease are diagnosed, treated and cared for, advocacy can help you to do this. This section on advocacy contains a step-by-step approach to show how you can develop and execute a plan to engage with policymakers. Advocacy is for everyone - all it takes is a good plan!

1. Your goals

Define what you want to achieve

Examples:



Improve access to treatment



Decrease risk of infection



Encourage effective telemedicine



Help rare liver patients understand how COVID-19 affects them

Tips

- Define:
 - what you want to achieve in both the short-term and the long-term
 - how this will benefit patients
 - if this is a realistic goal
 - what problems or things might get in the way

Defining this helps you to be prepared and have a better chance of reaching your goal.

- Be informed and understand what is already going on. Look in your own environment and check:
 - what European or national patient associations say
 - what professional societies are saying (look on the websites and social media)
 - what individual healthcare providers are saying (check LinkedIn and Twitter, as some are very active!)

2. Your messages

Write a clear and simple message that includes **AN ACTUAL, CONCRETE ASK** to help you reach each goal.

Examples:

- 1 Liver disease patients need medical care despite COVID-19. Where possible, liver services should be organised in a way that allows patients to be treated during the COVID-19 pandemic. Postponing treatment will lead to deteriorated health and insecurity for liver patients.

- 2 Healthcare providers should communicate clear information about how they are operating to minimise COVID-19 risks. Patients need reassurance so that they seek urgent care as soon as they need it.
- 3 While access to treatment is crucial for liver disease patients, everything possible must be done ensure that treatment in hospitals and physicians' offices does not increase the risk of infection with COVID-19. For each case, a benefit risk analysis must be made.
- 4 Telemedicine, where possible, should be encouraged, as long as this does not affect the quality of the treatment of liver patients.
- 5 One of the biggest challenges for liver disease patients knowing which COVID-19 information is reliable and trustworthy and understanding it. **Lay versions should be published for key scientific publications and literature reviews.**

Tips

- Keep messages clear and simple
- Include a concrete ask in each message so message is more than simply raising awareness
- Link your goals to current European/national/regional policies to increase interest

3. Who can help



- National ministry of health
- Members of national parliamentary committees on health
- Members of European Parliament
- European Commission (Directorate-General for Health and food safety – DG SANTE)



- Professional liver disease societies for hepatologists (eg Croatian Society of Gastroenterology)
- National and international umbrella liver patient associations
- ERN RARE LIVER

Tips

- Look on social media for politically active healthcare professionals.
- Look at the ENVI (European Parliament Committee on the Environment, Public Health and Food Safety) committee and equivalent national committees.
- Work with other patient organisations to make joint messages
- Sirpa Pietikäinen @spietikainen (Member of the European Parliament active in the field of rare diseases)
- Stella Kyriakides @SKYriakidesEU (European Commissioner for Health and Food Safety)
- Pascal Canfin @pcanfin (Chair of the Environment committee of the European Parliament)
- Tilly Metz @MetzTilly (Member of the European Parliament & active in the field of rare diseases)
- EU Commission's DG Health & Food Safety (SANTE) @EU_Health <https://ec.europa.eu/health/>
- ERN RARE LIVER @ERN_RARE_LIVER <https://rare-liver.eu/>
- EASL @EASLedu <https://easl.eu/> (note that EASL will not engage in any political opinion)
- Possibly other members of the European Parliament (preferably members of the ENVI committee) <https://www.europarl.europa.eu/meps/en/home>

4. How you can reach them



Search online for email addresses of policymakers. You can often find them on national/ European parliament or the health ministry websites. Email is common practice and widely accepted.



It is unusual for policymakers to answer directly but you might be able to make an appointment for a (virtual) meeting.



You may be able to connect with policymakers during (virtual) events. Asking a question (if you have one that is relevant to the event topics) will help raise the profile of your goal or ask.



The easiest way to reach policymakers is through social media. If supportive stakeholders endorse or share your messages, you reach an even bigger audience.

Tips

Preparation

- Identify which relevant activities the stakeholder has conducted and how much knowledge they have.
- Look at previous events they visited or search through parliamentary inquiries which were submitted.
- Go the extra mile and search for upcoming events that are relevant. Try to include in your messages to underline your statement and pressurise your message recipient.
- Examples include upcoming elections, reform of healthcare systems, political discussions on treatment and surgery during COVID-19

In the meeting

- Keep your communications short. Try and fit everything you want to say in a few key sentences.
- Make a good first impression.
- Introduce yourself, address your issue briefly and ask who you can send further information to via email.
- Do not make demands. Policy makers are interested in topics of potential voters in their policy field.
- Tailor your message to each stakeholder you are addressing
- In covering letters, include:
 - Brief explanation of your goal
 - Share your personal story or why you are interested in this topic

After the meeting

- Always follow-up
- Once you're in touch with policymakers, particularly after a (virtual) meeting or event, it is important to stay in touch. This can be done by using social media, sending a follow-up email. Use the follow-up to express gratitude and to update the policymaker about relevant events or policy developments. Maybe also include the action points you agreed on. This is an essential part of the process and should not be forgotten.

5. Examples of social media messages for advocacy purposes

- 1 Telemedicine is a useful tool during COVID19 but are we learning what works well and what does not? Hospitals must be properly resourced to deliver telemedicine well.
- 2 Telemedicine, while a useful way to deliver care during a pandemic, can never replace face-to-face care for liver patients. How can we harness the benefits of telemedicine to complement in-person care, now and beyond #COVID19?
- 3 9 in 10 #RareDisease patients are experiencing an interruption in care because of #COVID19 (via @eurordis). Treatments and procedures cannot be postponed - patients should be able to access care outside places where the risk COVID-19 infection is high.
- 4 To reduce the risk of exposure to #COVID19 for vulnerable liver disease patients, we call for minimum standards to facilitate telemedicine, ensure reduced physical contact and separate waiting rooms. @Minister of Health @member of health committee @spietikainen
- 5 Treatment of patients during #COVID19 varied markedly between EU Member States. The European Commission should set up guidelines to protect vulnerable groups during public health emergencies. @EU_Health @SKYriakidesEU @pcanfn

Organise your own event

Bringing people together to discuss topics can be a very successful way to raise awareness. If you organise an event, you should go through the same preparation as for a meeting. Clearly define who should be invited, what should be their role, identify the goal you want to achieve and why this structure will help you to achieve that goal.

Possible events include:

- Digital events and webinars: Due to COVID-19 this has become a very common way to organise events

After COVID-19:

- Parliament event
- Lectures/workshops
- Community lunch with policymakers