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## Nothing About Me Without Me: Shared Decision-Making in Chronic Hepatitis B

# Hepatology

# Nothing About Me Without Me: Shared Decision-Making in Chronic Hepatitis B

This GSK-sponsored symposium took place at the European Association for the Study of the Liver (EASL) International Liver Congress (ILC) on 23<sup>rd</sup> June 2022, London, UK



<b>Speakers:</b>	Mark Douglas, <sup>1</sup> Ahmed Elsharkawy, <sup>2,3</sup> Catherine Freeland, <sup>4</sup> Natalia Sadowska <sup>5</sup>
	<ol style="list-style-type: none"> <li>1. Viral Hepatitis Pathogenesis Group, Storr Liver Centre, The Westmead Institute for Medical Research, Sydney, Australia</li> <li>2. Queen Elizabeth Hospital, Birmingham, UK</li> <li>3. University of Birmingham, UK</li> <li>4. Hepatitis B Foundation, Doylestown, Pennsylvania, USA</li> <li>5. Member of the GSK Patient Council</li> </ol>
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## Summary

This GSK-sponsored symposium took place at the European Association for the Study of the Liver (EASL) International Liver Congress (ILC) on 23<sup>rd</sup> June 2022 in London, UK. The symposium was developed in collaboration with external experts, including people directly affected by hepatitis B infection, to help highlight priorities for communications between patients and healthcare professionals (HCPs) to ensure good patient outcomes. The panel members were Mark Douglas, a virologist at Westmead Institute for Medical Research, Sydney, Australia; Ahmed Elsharkawy, a consultant transplant hepatologist at the Queen Elizabeth Hospital in Birmingham, UK; Catherine Freeland, Public Health Programme Director at the Hepatitis B Foundation, Doylestown, Pennsylvania, USA; and Natalia Sadowska, who has chronic hepatitis B (CHB), and is a member of the GSK patient council. The symposium was a conversation between the panel members to help better understand the

key patient communication priorities for people with CHB when interacting with their HCPs. Panel members discussed the disconnect between patients and their HCPs in information sharing and treatment decision-making. The symposium also explored the patient journey to diagnosis, patients' fear of transmitting the virus to others, and the management of CHB in the current therapeutic landscape and the future as a functional cure becomes possible.

## Introduction

Hepatitis B affects more than 296 million people worldwide, according to the World Health Organization (WHO). More than 1.5 million new infections occur each year, despite the availability of safe and effective vaccines.<sup>1</sup> The virus is endemic in many countries, where it is most commonly spread through perinatal transmission or via exposure to infected blood during the first 5 years of life.<sup>1</sup>

In 95% of cases, if the virus is acquired before age 5 years, CHB infection results. In contrast, when hepatitis B is transmitted through needlestick injury, or exposure to infected blood or body fluids during adulthood, an acute infection generally occurs, with fewer than 5% of cases resulting in chronic infection.<sup>1</sup> But this information is not always shared with patients, and confusion exists among patients and HCPs about the risks of transmission and the best way to manage living with chronic hepatitis.

During the symposium, Sadowska, a 36-year-old female with chronic hepatitis infection, shared her story of how she came to be diagnosed with CHB during routine blood tests when she was pregnant with her first child, and how the diagnosis affected her and her family. She outlined how the knowledge affected her at diagnosis, and subsequently during treatment. During the discussions, Sadowska and the other panel members shared their experiences and opinions on what more can be done to communicate with patients to empower them to make choices about their own and their family's health and wellbeing following diagnosis.

Freeland chaired the session and raised several questions that helped to highlight the issues that patients and HCPs face, and how better communication and understanding could improve outcomes for people affected by hepatitis B.

## Do People with Hepatitis B Experience Stigma and How Can That Be Addressed?

Sadowska was diagnosed with hepatitis B, aged 32 years, while pregnant with her first child. "After some routine antenatal tests, I got a letter from the Health Authority telling me that I had hepatitis B. That was the first time I knew I had the virus," she explained. At a follow-up appointment, Sadowska was told it was a chronic infection, that her partner should be vaccinated, and that the baby would be vaccinated at birth. "I felt like I'd done something wrong. I really didn't know how I could have caught the virus," she continued. Sadowska's general practitioner referred her to a specialist, but 6 months elapsed before she got an appointment. "My doctor told me that although the infection was chronic, my liver was fine, so I didn't think it was urgent or anything," she said.

Freeland explained that it is common for people to feel like they have done something wrong when receiving their diagnosis. She asked the other panel members whether they had witnessed patients self-stigmatising in their clinical practice.

Elsharkawy answered: "Yes, we often see stigmatisation. There is a lack of awareness of how the virus is transmitted, which is a problem, even within healthcare systems. I've heard colleagues ask, 'Were you sexually promiscuous?', which automatically puts people on the defensive."

"We need to change the conversation from a 'blame game,'" he continued, and added: "It is a real big stumbling block for diagnosing and engaging with people living with hepatitis B."

Douglas explained that misunderstandings around how the virus is transmitted are common. "Sometimes patients come from an endemic country and may have had the virus since birth.

The infection only comes to light when tested because they are pregnant, or as part of a screening programme.” He explained that the patient can feel guilt and family members and friends can be judgemental, and went on to assert: “We need to raise awareness that if you are born in an endemic country, that is enough to acquire the infection.”

Later in the session, a member of the audience raised the question of how we address this stigma among the public, patients, and HCPs. Elsharkawy responded: “We need to start the conversation and deal with it on a human level. As HCPs, we need to encourage our patients to talk about their experiences of living with hepatitis B and the barriers they face. Until we have that two-way conversation, we are not going to change things.”

Douglas agreed, and added: “People need to know this is a common infection. Even within healthcare settings, I’ve had nursing students tell me they might not be able to do a placement if they have hepatitis B. They should not be discriminated against.” He went on to emphasise the importance of advocacy groups and speaking to community leaders to help understand and address the issues of discrimination at a local level.

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### How Can We Better Explain How the Virus Is Transmitted?

When Sadowska was diagnosed, she was advised that her family members should be tested to see if they were carrying the virus, but no one explained to her what the virus could do to her body. Freeland asked her if there was anything she wished she had known in those early days. In response, Sadowska said: “I wish I had known how easy it can be transmitted to a baby at birth, and that the vaccination does not work from day one.” She added that she was asked if her mother had the virus, but no one had mentioned it was also a sexually transmitted disease.

Freeland then asked Douglas and Elsharkawy to recommend how to communicate a hepatitis B diagnosis effectively to patients. Douglas began by saying: “I would explain how it is transmitted, that you can catch it when you are a baby, and

that there is a 95% chance you will develop a chronic infection for life. Whereas if you are exposed as an adult, it is the opposite, and you have only a 5% chance of a chronic infection. Most people infected as adults clear the infection over a few months.” He continued by saying that it is crucial that the patient is not made to feel isolated or guilty, and that it is made clear to them that the vaccine does not work if the individual is already infected with the virus.

Elsharkawy agreed, and emphasised that clinicians need to talk to their patients about breastfeeding. “There is a lot of misinformation in the public domain about the risks of breastfeeding and virus transmission, which will be one of the main concerns for pregnant women. The risk of transmitting the hepatitis B virus through breast milk is very low, which should be made clear to the patient,” he said. “A recent meta-analysis of studies suggests that the risk is very low,”<sup>2</sup> he added. “Patients are understandably worried about the risks to their baby, and also want to know how effective the vaccine is in babies and what will happen if the baby gets the virus.”

Sadowska agreed that understanding the low risk of hepatitis B transmission through breastfeeding is important, and said: “I was told at the beginning that breastfeeding was not a risk, and I was happy about it. But there is something else that comes with breastfeeding that concerns every single woman, and that is you can get cracked nipples, and there is blood involved, and this is a route of transmission. I wasn’t aware then that the virus could be transmitted via blood.” Sadowska continued: “My doctor assured me that my daughter would have to be injured in some way and touch the blood from a wound to get the virus that way.”

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### How Can We Explain the Complexities of Viral Immunity to Patients?

“One of the things that never came through in the conversations I had with my doctors is that once you have had the virus, you have it for life,” Sadowska asserted. “Doctors say you’ve had the virus, and you fought it off, and you are fine. But you might not be fine later when your immune system gets weaker for whatever reason.”

Freeland asked the other panel members to explain how they communicate the complexities of viral immunity to their patients. Elsharkawy said: “We need to be clear with patients what we mean by cure. What I say to patients is that your body has fought off the infection, the virus is low and is unlikely to cause any damage in the future, unless you require treatment for another condition that suppresses the immune system, such as chemotherapy for cancer, in which case the virus may return.”

Douglas added that explaining the complexities of hepatitis B infection and immunity to the virus is challenging, and even medical students and general practitioners can struggle with the concepts. “It is important to talk to the individual and find out how they want to approach it and how far they want to go in understanding. The more they ask, the more information you can give them. You don’t need to explain everything at once. You can have an immediate goal of where we are at and what we are aiming for in terms of cure. You can always discuss the caveats later.” Douglas added: “Too much information at one time can be a problem.”

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### When Should We Use the Term Patient?

Many people affected by disease prefer not to be described as a patient. For them, it suggests they are not actively involved in their own care. Freeland asked Sadowska how she felt about being referred to as a patient. “I started feeling like a patient when I found out I needed to go on medication. Until then, I didn’t feel ill, and I wasn’t thinking of myself as a patient. But when I started treatment, I started getting some symptoms, including stomach pain that may have been psychosomatic. I was much more conscious of my body and how it reacts. I’m on medication for the rest of my life, so I am a patient.”

Elsharkawy added: “For some people, it is not appropriate to refer to them as ‘patient’. As a clinician, it’s important to be culturally aware and sensitive to differences among patient populations. Perhaps we should ask the question, ‘Are you happy to be called a patient?’ This is particularly important when it comes to advocacy; when someone is asked to raise their voice and share their story, it is essential

to establish an agreed language that people feel comfortable with.”

Douglas noted: “Some people are happy for the doctor to make choices. Others are more actively involved. We need to respect them and treat them as an individual, and adjust our interaction with them if necessary.” Freeland agreed, saying: “It is important to have those conversations. For most people, there are lots of things going on in their lives that go beyond having hepatitis B.”

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### What Do We Know About the Symptoms Associated with Hepatitis B Infection?

“Often clinicians see hepatitis B as an asymptomatic disease, and yet many patients experience symptoms,” explained Freeland, which makes many people feel unheard by their practitioners. Sadowska agreed, saying that she only became aware of her symptoms when she started reading about what symptoms she might get. “It may be psychosomatic, but I experience pain on the right-hand side around the liver. It comes in waves, not every day. I wasn’t aware of it before I started reading about medications. But my doctor told me that it was not possible to feel liver pain until late-stage disease, so it was not possible for my pain to be liver pain.”

Elsharkawy explained: “Traditionally, we say the liver disease is asymptomatic, but there are symptoms and impairments to quality of life that may be subtle, but they are still there.” He continued: “The story I sometimes hear when I start someone on a new medication is that I didn’t realise how fatigued I was until I was on medication, and now I feel a lot better. We need to better understand the mechanisms of liver inflammation, because even if inflammation is dampened, some people are still plagued by fatigue.” Freeland concurred, and added that the fear of liver cancer is a concern for people with CHB infection and often in people’s minds.

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### Can We Do More to Support Patients When Discussing Treatments?

Freeland asked Sadowska about her experience of finding out she needed treatment for her



hepatitis B. Sadowska described how at a regular follow-up appointment, she was told her liver enzymes were raised slightly, and the doctor wanted her to start medication, which she accepted. However, she said: “My initial reaction was that this was bad, and I wondered what time I had left. Is this the end, or is it coming? I didn’t have any other questions. It came as a shock that the liver was not doing that well.” Sadowska left the surgery and started researching at home, and that is how she found out that hepatitis B infection can lead to cirrhosis and liver cancer. “That was when I started feeling slightly ill with stomach pain,” she explained.

Elsharkawy responded that starting treatment does not need to be an immediate decision. “I might say to a patient, you may need treatment in the next year or two as the virus levels are starting to creep up. Your alanine aminotransferase (ALT) level is okay. We can afford to wait 3 months, but I want to see you in 3 months rather than 6 months. This gives them time to get used to the idea that treatment may start soon. Then I explain what treatment entails and what the potential side effects might be.”

Douglas added: “The virus load may have been stable for a long time, and suddenly it jumps right up.” Some people want to start treatment straight away, whilst others need time to decide. But it is important to emphasise that once you start treatment, you need to keep going because if you stop and start, you can get flares. “The treatment will control virus levels so they don’t damage the liver, but it is not a cure,” he said.

Elsharkawy added that it is important not to underestimate the psychological impact on a young person of starting daily medication. “If you don’t do the preparatory work, people struggle with adherence,” he said. Douglas added: “People might find it difficult to take a tablet daily. Something straightforward like blister packs marked with days of the week can help.” Others use phone apps, and incorporate taking the tablet with a daily activity that is already part of their routine.

This resonated with Sadowska, who was not given any tips on adhering to her daily medication. She agreed with other panel members that the psychological aspects can be difficult. “No one in my family or circle of friends

had been properly ill. Suddenly I’m told I need to take something for the rest of my life, every day, and the list of side effects is long. It was difficult, and I felt very vulnerable. I felt like I was going to die soon.”

Listening to Sadowska’s comments, Elsharkawy realised he needed to reflect on his practice and remember to make it clear to patients that when they start treatment, it is to prevent something that might happen in 5–10 years, and there is no imminent danger. “We don’t emphasise that enough,” he said.

Douglas agreed, saying: “I think perhaps I’ve underestimated that patients will feel threatened when they start treatment.” For Sadowska, starting medication had a huge impact. “I was still breastfeeding my second daughter when I was told I needed to start medication immediately, and maybe I could have waited a month or two. It was a difficult time to stop breastfeeding overnight.”

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### What Does Functional Cure Mean and How Should We Communicate It to People with Hepatitis B?

People who test positive for the surface antigen of hepatitis B virus (HBsAg, also known as s-antigen) are considered infectious,<sup>3</sup> and a functional cure describes patients who no longer have detectable s-antigen in their serum.<sup>4</sup> “People want to get rid of surface antigen,” said Freeland. “How do you explain to people what that means?” she asked the panel.

“It is a tough one to explain,” Douglas responded. “There are new treatments under investigation which aim to get rid of the virus within 12 months. This will take a combination of treatments. Clinical trials are underway.” He said: “We explain to people that participating in the trial may mean there is a chance of cure, but at the moment, we don’t know whether that is a 30% or 50% chance. You will have to take an extra pill or injection once a week or once a month for a defined period. Some people will leap at it. Others are comfortable with what they are on, or hate the idea of an injection.”

For Elsharkawy, the term functional cure is a difficult one to explain. “We need to look fundamentally at why we are trying to achieve s-antigen clearance, and the reason seems to be that your risk of liver cancer is significantly reduced.<sup>5</sup> Perhaps we should talk about a ‘road to cure’. We don’t know whether, if you clear s-antigen and you get an adaptive immune response, that with time you eventually get rid of closed circular covalent DNA in the liver. No one knows yet.”

Douglas added: “We should be talking about ‘eradication’ not ‘cure’ when you have cleared the virus and don’t need to be on treatment. There is still a template of the virus in your liver, and if you get immunosuppressed, there is a chance it could come back.”

Sadowska voiced her concern about not being cured, saying: “I’m worried that I am still

infectious and I could give the virus to someone. If one of my daughters tries to drink from my cup, I snatch it away from them, although I know my virus levels are really low. I keep thinking about it. Being functionally cured, it would be a nice change.”

Freeland reiterated the importance of getting a functional cure for people. “In some countries, the presence of s-antigen can determine whether or not someone gets a visa.<sup>6</sup> It has a discriminatory impact.” She then asked Sadowska what functional cure means for her.

“The important message is that the virus could come back. People need to be cautious,” Sadowska replied. “I would be prepared to go through more aggressive treatment to get cured. Yes, I would be part of a clinical trial, I would go wherever, or whenever is needed, but I work full time and am a mum, so there are limits.”

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