Education helps to reduce stigma and helps people understand that it is not your fault if you have hepatitis C.

Shabana Begum
Want to share a feature for Hep Voice?
Share your news or story by emailing contact@worldhepatitisalliance.org
Liver Cancer Awareness Month
October 2023

Viral hepatitis infection is the most common risk factor for liver cancer. Chronic viral hepatitis can lead to hepatocellular carcinoma (HCC), which accounts for 80% of all liver cancer cases and is the third most common cause of cancer deaths worldwide. Liver Cancer Awareness month in October is a significant month for hepatitis advocates globally to raise awareness about the virus and call for viral hepatitis programmes to be integrated into cancer prevention programmes globally. Get involved here.

World Health Summit
15-17 October 2023

The World Health Summit is an international strategic forum for global health which brings together stakeholders in politics, private sector, civil society and science to develop innovative solutions for a healthier future for all. With the theme “A Defining Year for Global Health Action”, the summit will be held in Berlin, Germany and online. Find out more here.

World Mental Health Day
10 October 2023

This year’s theme of World Mental Health Day is “Mental health is a universal human right.” People living with chronic hepatitis often suffer from depression and anxiety due to several factors, including stigma and discrimination. World Mental Health Day is a significant date to drive positive action for the mental health of people living with hepatitis, including tackling the stigma and discrimination attached to the virus. WHA’s stigma report sheds light on the effects of stigma and discrimination faced by some people affected by hepatitis B. Read the report here. Find out more about World Mental Health Day here.

World Food Day
October 16

Hepatitis A and E viruses can be transmitted through contaminated food and water. Food safety is a shared responsibility. Everyone including governments, organisations, civil society and individuals must take action for the future of food, people and the planet. You can participate in the World Food Day Poster contest to showcase your creativity by designing a poster that illustrates your efforts for promoting food security. Find out more here.

European Testing Week
20-27 November 2023

Nine out of ten people living with viral hepatitis are unaware they have hepatitis. European Testing week is an opportunity for partner organisations to unite across Europe to promote awareness of the benefits of early hepatitis and HIV diagnosis. This initiative has progressed since its inception in 2013 and marks its tenth-year anniversary this year. Find out more here.

World Aids Day
1 December 2023

Globally, there are about 38 million people living with HIV. Chronic liver disease represents a major cause of morbidity and mortality among persons living with HIV globally. World Aids Day is an opportunity for people across the world to join efforts to fight against HIV and AIDS-related illnesses. Find out more here.

Human Rights Day
10 December 2023

Human Rights Day is observed every year to commemorate the Universal Declaration of Human Rights (UDHR) adopted by the United Nations General Assembly in 1948. This year marks the 75-year anniversary of the UDHR. It is these basic rights, that form the framework for highlighting and addressing the inequalities which characterise the global response to hepatitis elimination. Human Rights Day is another chance to raise awareness for people living with viral hepatitis. Find out more here.
Let’s look at some of the latest hepatitis news from around the world.

**Medical visionaries at EASL Congress 2023**

The NOhep Medical Visionaries met at EASL Congress in Vienna, June 2023, to explore the barriers to accessing care and discuss solutions to make the elimination of viral hepatitis a reality. The session was facilitated and led by Dr Ahmed Elsharkawy, Honorary Senior Clinical Lecturer at the University of Birmingham, who was joined by Partizan Malkaj, Director of Albanian Hepatitis Organization and Rachel Halford, CEO of The Hepatitis C Trust.

Key themes discussed included:

- **Cost:** The financial burden on patients with hepatitis C and their caregivers is high, making cost a barrier to care. The patient-borne costs associated with hepatitis C infection are often misunderstood, most cost-of-illness studies estimating only the direct medical costs of hepatitis C.

- **Testing in A&E:** London A&E departments have recently adopted opt out testing for HIV, hepatitis C and hepatitis B. This has resulted in a number of new diagnoses, in particular for hepatitis B where they have found three times as many people living with hepatitis B than HIV or hepatitis C.

- **Linkage to care for hepatitis B:** Increasing access to screening is a crucial step towards achieving the elimination of hepatitis B. However, the opt out testing in London A&E departments has highlighted that screening programmes must ensure that a pathway to care is included.

- **Under representation:** People living with hepatitis B are not well represented; advocates are missing in local communities and in public life, and personal testimony is minimal – this has resulted in a lack of confidence in communication, and people feel inhibited or anxious in coming forward to ask for information or support.

**World Hepatitis Summit 2024**

Early bird registrations are open for the World Hepatitis Summit 2024!

Registrations are now open to attend the World Hepatitis Summit (WHS) in Lisbon. The summit takes place in Lisbon, Portugal from 9-11 April, 2024.

The summit is organised by the World Hepatitis Alliance with the support of the Ministry of Health of Portugal. With the theme, “Integrate, Accelerate, Eliminate,” the summit will put the voices of people living with viral hepatitis front and centre.

WHS 2024 will bring together community organisations, policy makers, government, advocates, medical professionals, the private sector and donors to make the dream of hepatitis elimination a reality.

The global community will share and learn about the innovative work being done to increase access to testing, vaccination, and treatment services. They will also share strategies to tackle stigma and discrimination, advocate and campaign for funding, with an aim for viral hepatitis elimination by 2030.

Registrations are available for virtual and in-person attendance. Early-bird registrations are open until midnight (GMT) on Friday 19 January 2024. Register [here](#).

Learn more about the NOhep Visionaries Forum [here](#).
**Hepatitis B and C higher cancer risk than smoking a daily pack of cigarettes**

New research by the Centre for Disease Analysis (CDA) Foundation found that hepatitis B and C viruses are highly oncogenic leading to cancers in multiple organs and sites. The report finds that hepatitis B and C infected individuals “have a similar or significantly higher risk of developing cancer than someone who actively smokes one pack of cigarettes per day.” It concludes that hepatitis B and hepatitis C should be “considered as cancer causing infections and international guidelines should be reconsidered accordingly.”

A recent survey from WHA also found that nearly half (42%) of people globally are unaware that one of the leading causes of liver cancer is viral hepatitis. Nearly three quarters (74%) of those surveyed say knowing hepatitis causes liver cancer means they are more likely to get tested and over four fifths (82%) say they are more likely to get vaccinated.

Globally, over 350 million people live with hepatitis B or C, causing more than 1.1 million lives to be lost each year. By 2040, deaths from viral hepatitis are expected to exceed mortality from HIV, malaria, and tuberculosis combined.

CDA’s research was included in WHA’s recent World Hepatitis Day activity. Find out more [here](#).

**Mortality rates high despite hepatitis C cure**

A recent study found that adults successfully treated for hepatitis C infection still face a substantially greater risk for death compared with the general population. The primary factors contributing to the higher mortality rates were deaths linked to liver issues and drug-related incidents.

Based on their findings, the authors emphasise the need for continued support and follow-up after successful treatment for hepatitis C to maximise the impact of direct acting antivirals. Read more [here](#).

**Hepatitis C rates skyrocket among pregnant women in US**

New research revealed a 16-fold rise in the prevalence of hepatitis C virus infections among pregnant women over the course of 21 years in the US, linked to the opioid epidemic. This surge increases the likelihood of compromised foetal development, premature birth, and foetal distress, a condition where the baby does not receive adequate oxygen via the placenta during pregnancy or labour.

The lead author of the research emphasises that this trend should spur healthcare providers to initiate universal hepatitis C screening for pregnant women in the US. Read more [here](#).
In July, representatives from 18 community-based organisations and experts from 11 countries in the Asia-Pacific region came together at a workshop to exchange ideas on effective elimination strategies for hepatitis B by 2030.

The World Health Organization (WHO) estimates that 296 million people worldwide live with hepatitis B, with Asia representing more than 50% of people globally living with chronic hepatitis B and C. Each year over a million people lose their lives to hepatitis and chronic infection that cause liver cancer and cirrhosis. Viral hepatitis is the leading cause of liver cancer, with Asia Pacific having some of the highest liver cancer rates globally.

The two-day 2023 Asia ‘Hep Can’t Wait’ summit offered delegates insights on the region’s progress in elimination of the disease. The summit sessions gave participants the opportunity to discuss topics such as improving access to testing, care and treatment for people living with viral hepatitis. Crucial areas discussed included novel approaches to financing as well as the implementation and integration of innovative hepatitis services allowed for exchanges of best practices that can be adapted and applied across different geographies in Asia.

Groups in attendance included Cancer Information Hong Kong, The Hong Kong Liver Transplant Patients’ Association, Japan Hepatitis Council, and Taiwan Young Patients Association.

One of the key takeaways from the workshop was the pivotal role of communities in the hepatitis response, and the need for collective action to catalyse greater change. This culminated in a consensus statement by the community-based organisations.

This consensus marks a significant milestone in the fight against viral hepatitis and affirms the Asia-Pacific region’s commitment to accelerating hepatitis B elimination efforts and adopting a multi-sectoral collaborative approach. Learn more here.
CONSENSUS STATEMENT

The Asia Pacific region is disproportionately impacted by viral hepatitis, accounting for approximately 70% of all viral hepatitis-related deaths globally. These deaths are driven in large part by hepatitis B, with approximately 150 million people in the region living with this life-threatening disease. Without care and treatment, hepatitis B is a leading cause of liver cancer and cirrhosis. However, no one should die from or be impacted by hepatitis B, it is entirely preventable.

With a significant expansion of affordable and accessible vaccination, testing, care and treatment, we can reach the World Health Organization goal to eliminate hepatitis B by 2030 in the region.

People with lived experience and community groups are integral to driving the response by bravely sharing their stories, delivering innovative programming, challenging stigma and discrimination, advocating for policies to improve access, and supporting those living with hepatitis B. The ongoing involvement and leadership of people with lived experience and community groups is critical to achieving the elimination goals.

To drive transformative change within the region, countries must adopt a resourced public health response centered on human rights and the lived experience of people with hepatitis B. Within this response, we call for the following:

- Testing strategies must be co-designed and delivered by public, private and community-based services that utilise innovative point-of-care screening and diagnostic tools which are well-integrated with existing one-stop testing services.
- Person-centred testing, care and treatment must be decentralised, integrated and coordinated across all levels of the health system and within communities to better facilitate knowledge transfer and improve coverage, equity and accessibility.
- Universal Health Coverage must include hepatitis B to improve access to prevention, testing, care and treatment. There should be coordinated efforts between payors and stakeholders across the care cascade to remove financial barriers to access guideline-based care.
- There must be sufficient resources and capacity to support linkage and retention to care. The risk of self-discontinuation in care is very high due to various factors, such as internalised stigma and socioeconomic factors amongst others, contributing to many people diagnosed with hepatitis B not in care.
- To reduce stigma, governments must increase health literacy around hepatitis B in the general population, recognising the importance of empowering young people to drive awareness and education within families and communities.
- Governments, health care systems and private sector organisations must adopt and enforce laws, policies and practices to protect the equal right of people living with hepatitis B to enable them to live their lives free of discrimination or disadvantage.

Hepatitis Can’t Wait.
The Hep Can’t Wait Asia Workshop took place 11-12 July 2023 in Hong Kong.

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How has living with hepatitis B impacted your daily life?

I take medication daily which isn’t a big deal in the grand scheme of things. However, it reminds me that my liver isn’t normal and that I’ll be taking it for the rest of my life unless a functional cure is developed.

This year’s WHD theme is “We’re Not Waiting”. As a hepatitis B advocate, what are you not waiting for?

As a hepatitis B advocate, I’m not waiting for hepatitis B to become “popular” enough for changes to be made. I’m demanding that viral hepatitis elimination be made a priority worldwide.

What’s your advice to young people living with hepatitis B?

Advocacy and storytelling are the most powerful tool we have as younger patients. Consider how powerful a voice of young people living with hepatitis B could be if we all became active advocates. My last words of advice are to live as healthy as you can while not judging yourself too harshly.

Watch David’s story here.

WHA has launched a film series called “I Can’t Wait”, which captures the lives of people living with hepatitis and thriving in their personal lives. The video series aims to change the way people and decision makers think about people living with hepatitis – to build empathy, understanding and to drive action for change. The videos will amplify the voices of people affected by viral hepatitis calling for immediate action and the end of stigma and discrimination.

Why did you choose to be part of this film?

I chose to be a part of this film because I wanted to show that having chronic hepatitis B hasn’t held me back from doing the activities I love the most. When I was diagnosed at 13 years old, I felt my life was over. I want people who view the film to be inspired to follow their passions and to always remember that hepatitis B is a part of us but it doesn’t make us who we are.

How has sharing your story made you feel?

Sharing my story has made me feel like I’m in control of my illness. It has connected me with the greater hepatitis B community for which I’ll be forever grateful. Stigma and discrimination will never go away unless we all share our stories and that will always motivate me to continue sharing.

What has kept you motivated since you were diagnosed with hepatitis?

What keeps me motivated is my family, friends, loved ones, passions, and every single human being that has ever been impacted by viral hepatitis.
We call on funders to integrate viral hepatitis into their programs for equitable and people-centered healthcare.

Since the last World Hepatitis Day, The Global Fund has made a commitment to expand support for hepatitis-related services which will bring hope for so many communities.

Although there has been progress, we still face many challenges. Liver cancer related to hepatitis is on the rise around the world, especially in low- and middle-income countries. Stigma and discrimination continue to be a barrier to testing and care; and globally more than 350 million people are still living with this life-threatening disease.
GLOBAL HEALTH ENGAGEMENT ON WORLD HEPATITIS DAY!

- WHO launched its “One life, one liver” campaign calling for scaling up testing and treatment for viral hepatitis. Read more here.

- WHO Director-General Dr Tedros Adhanom Ghebreyesus shared a World Hepatitis Day 2023 video statement. Watch it here.

- Danjuma Adda, President of World Hepatitis Alliance joined the WHO webinar with the theme “One Life, One Liver”, to discuss scaling up the testing and treatment of viral hepatitis towards the 2030 elimination goals. Read more here.

- Members and MPs from UNITE, the Parliamentarians Network for Global Health showed support for the WHD virtual relay. Hon. Éctor Jaime Ramírez Barba (from Mexico), Hon. Akaki Zoidze (from Georgia) and Hon. Karti Chidambaram (from India) supported WHD on videos shared on social media and hosted on a blogpost on UNITE’s website. Read more here.

- The Hepatitis C Trust called on UK governments to not miss the target of eliminating hepatitis C in England and Northern Ireland by 2025, in Scotland by 2024/25 and in Wales by 2030. The Hepatitis C Trust used the theme ‘Don’t miss the target.’ Read it here.

- The Coalition for Global Hepatitis Elimination’s (CGHE) Director Dr John Ward joined a PAHO webinar discussing scaling up access to diagnosis and treatment to save lives. Watch it here. CGHE also shared a blog post about the Local Hepatitis Elimination and Prevention Program in Rawalpindi, Pakistan. Read more here.

- Dr Jean Kaseya, Director General at The Africa Centers for Disease Control and Prevention (CDC), shared a speech for WHD on Africa CDC’s commitment to eliminate viral hepatitis in Africa. Watch it here. Africa CDC and The African Union also shared a WHD blog post on hepatitis awareness and vaccination. Read it here.

- The European Liver Patients’ Association (ELPA)’s President Marko Korenjak posted a message on social media highlighting the importance of collaboration between governments, healthcare providers, researchers and patient advocacy groups to tackle the changes posed by hepatitis and liver cancer effectively. Read more here.
Every year, WHA members worldwide discover new and creative ways to raise awareness of viral hepatitis on World Hepatitis Day. United under the “We’re not waiting” theme, members showed their commitment to achieving viral hepatitis elimination by 2030.

Thank you to everyone who took part in WHA activities this World Hepatitis Day!
To address the challenges in scaling-up hepatitis elimination activities, in partnership with two WHA members in Nigeria, WHA has initiated a project which advocates for greater financing for viral hepatitis programmes in the country. To achieve this, the project includes these three pillars of work:

1. Deliver training for WHA members and other advocates to increase their ability to effectively advocate for financing for hepatitis programmes.
2. Raise awareness to increase the number of people demanding action by the Federal and State governments.
3. Influence policy makers to develop champions within the Federal and State Ministries who can help drive domestic and catalytic financing options forward.

On World Hepatitis Day (WHD), both WHA members in Nigeria recognised the importance of not only raising awareness, but also engaging with a wide variety of stakeholders. Below is a summary of their activities throughout WHD 2023.

WOMEN AND CHILDREN HEALTH EMPOWERMENT FOUNDATION (WACHEF), TARABA:

In an important step to help preserve the health of the community and prevent the spread of hepatitis, WACHEF staged a public lecture on preventative awareness at Muwanshat College of Health and Technology in Taraba. They also provided free testing and counselling services for hepatitis B and C, using the WHD theme, “we are not waiting”. The event witnessed a tremendous turn up of participants as over 100 people were in attendance with a guest speaker Dr. Sonnen Atinge from Public Health Department, Taraba State University, Jalingo.

CARE FOR SOCIAL WELFARE INTERNATIONAL (CASWI), CALABAR:

To help prevent the spread of hepatitis, CASWI conducted free hepatitis B screenings in Calabar. At the event, 327 people and 318 non-reactive people received their first hepatitis B vaccine shot, making sure that reactive people were counseled and referred to a secondary healthcare facility by the team of medical doctors present at the event. In addition to the screenings, 2,000 posters were distributed and posted across the streets of Calabar Municipal and Calabar South LGA, whilst radio jingles aired across the state and a 2km hepatitis awareness road walk was conducted in the city of Calabar, Calabar.
THOUSANDS OF VIRAL HEPATITIS CASES IDENTIFIED IN ENGLAND FOLLOWING NEW NHS ENGLAND TESTING SCHEME

NHS England initiated opt out testing in emergency departments for HIV, hepatitis B and hepatitis C in the areas of England with the highest diagnosed prevalence of HIV infection. Opt-out testing in emergency departments has been proven to be an effective approach in identifying and linking to care people who are unaware of their diagnosis to these viruses. This plan contributes significantly to the HIV action plan to end HIV transmission in England as well as WHO’s goal to eliminate viral hepatitis as a public health threat by 2030. Thousands of new HIV and viral hepatitis cases have been identified as a result of this new testing scheme.

Tell us about the Emergency Department Blood Borne Virus testing project. Why was this project commissioned?

This is a pioneering project whereby people attending emergency departments in areas of highest HIV prevalence are offered routine blood borne virus (BBV) tests, included in their usual blood tests. Posters and banners in commonly spoken languages inform about the testing, benefits, and how to opt out if people wish.

Working with brilliant charity partners, in particular the HIV Commission led by the Elton John AIDS Foundation, the Terrence Higgins Trust and the National AIDS Trust, the project started in April 2022, funded for three years by NHS England as part of the HIV Action Plan. The additional innovation came when we partnered with the NHS England Hepatitis C Elimination team to include hepatitis B and C testing, supporting the UK’s commitment to ending all three BBVs as public health threats by 2030.

We learnt from pilots in over 20 emergency departments, which demonstrated this approach reaches people less likely to access testing, avoids future healthcare costs by reducing transmissions, raises awareness of testing, and addresses stigma associated with BBVs.

What are its key findings?

33 emergency departments across London, Brighton, Blackpool and Manchester are offering opt out BBV testing, which has found over 3,000 people with a BBV (2,500 newly diagnosed and over 600 previously diagnosed but not in care). They are now being linked to care, treatment and peer support. This programme was scaled up rapidly across four cities, demonstrating the power of collaborative and integrated system working.

What do the findings tell us about hepatitis elimination in England / and on a wider scale?

Expanding testing for viral hepatitis using opt out testing in emergency departments is an important part of the national strategy for elimination of viral hepatitis. Focused hepatitis C testing has already led to the treatment of over 84,000 people, and testing in emergency departments is effective in finding new cases in people who have historic risks and people previously diagnosed but not in care.

High numbers being diagnosed with hepatitis B pose a challenge to services in some areas to ensure effective linkage and retention in care, leading to a review of clinical pathways. UKHSA will report fully on the strategy’s effectiveness in eliminating viral hepatitis in England in their evaluation.

Ian Jackson, Director of Contracts and Planning, London Specialised Commissioning Directorate, and Mark Gillyon-Powell, Head of Programme, HCV Elimination, NHS England tell us more about this programme.
Why has the opt out testing been so successful? What were the key elements of the success?

The leadership and enthusiasm of emergency department clinicians is key, helped by the fact that results management is facilitated by HIV, hepatitis or infectious disease teams, leading to high uptake in many hospitals. The willingness of HIV and hepatitis clinicians to train and support emergency department staff and feedback results is critical. As is securing buy-in from IT teams to make changes to Electronic Patient Record systems to enable automation of BBV testing requests and not ordering repeat tests for those recently attending.

People involved in the project really are motivated by seeing the results in almost real time, knowing that for everyone we find there is a real chance to help them from a health perspective, and link them to wider peer led services.

Shabana Begum, National South Asian Project Coordinator at Hepatitis C Trust shares her experience of living with hepatitis C and her work to eliminate the virus.

Can you please share your journey and how you were diagnosed with hepatitis C?

I was born in Yorkshire in the mid-1960s to a conservative Muslim family and spent most of my youth here. At the age of 13 my father decided to take us to Pakistan to educate us on our culture and heritage. During my stay I fell ill and my dad took me to the local doctor. I was prescribed medication and the doctor’s assistant injected me with a hypodermic syringe (metal and glass syringe). I later discovered that I had been injected with an unsterile syringe and contracted hepatitis C.

20 years passed and I was blessed with five children, but I had been feeling ill for a very long time. I approached my GP in the UK and requested routine tests to find out what was wrong. All of the results came back negative, so I requested further testing for HIV and hepatitis. After three weeks of waiting, I had a liver biopsy and was told I had liver cirrhosis and had hepatitis C in my blood for around 15 to 20 years.
received the results. I had tested negative for HIV but was positive for hepatitis C. I had a liver biopsy and was told I had liver cirrhosis and had hepatitis C in my blood for around 15 to 20 years.

Did you tell your family about your diagnosis, and how did they feel?

When I found out my diagnosis. I came home and told my mom that I had been diagnosed with hepatitis C. She immediately stopped me by asking her further questions and told me not to mention that name as it’s embarrassing and very shameful to talk about it. She also said that almost everyone she knew had it in Pakistan, it was as common as water!

When I mentioned my diagnosis to my big brother looking for some sort of support from him, he just asked where I had been to catch it.

Further conversations in my family revealed that my aunt and her children had died from hepatitis C and had all contacted the virus from treatment at the same doctor I had seen in Pakistan. I was devastated and heartbroken by the response and felt totally isolated and unwanted.

What support and advice were you offered by medical professionals?

My GP in Huddersfield, UK had no knowledge and asked me to bring back leaflets for him. I only met the consultant a few times but my hepatitis C nurse was supportive and gave me the relevant information and advised me to join a hepatitis C support group. This helped me to see how people were responding to hepatitis C treatment. I was on the old treatment – Ribovarin and interferon, and was horrified at the side effects that people displayed and talked about but I also knew that the only way of ridding myself of hepatitis C was to undergo this treatment.

What do you do and what does your work involve?

I am the National South Asian projects co-coordinator for The Hepatitis C Trust. I raise awareness of hepatitis C within the hard-to-reach communities, mainly South Asian communities engaging with organisations at grassroots levels, including community centres and religious establishments such as Mosques/Sikh Gurdwaras and Hindu Temples, and cover Melas (south-Asian festivals), and health days.

In my work I attend Operational Delivery Network (ODN) meetings and liaise with NHS teams to organise testing and successful delivery of the ODN events. I have helped in developing Hepatitis Awareness Treatment (HAT) Training and educating attendees on hepatitis C and transmission routes in Urdu and Punjabi.

I have been raising awareness of hepatitis C in the South Asian community for almost 20 years. Through education, people can understand how hepatitis C is transmitted and the importance of testing. Education also helps to reduce stigma and helps people understand that it is not your fault if you have hepatitis C. I have worked toward translating materials into Urdu, such as posters, banners, videos, and most recently a booklet. I have been regularly interviewed by local and national TV and Radio in Urdu, Punjabi, and English languages, and most recently was filmed for a WHA video. Last year I jumped out of a plane sky dive to help raise awareness and funds for the Trust.

How did living with hepatitis C affect your daily life and overall well-being?

It was difficult not knowing what was wrong with me after visiting my GP and requesting tests, and the GP could not find anything wrong with me. I was visiting him every two to four days, and suffered from aches and pains, flu-like symptoms, fever, severe headaches, exhaustion, mood swings, and IBS. I even underwent investigative keyhole surgery just to find out why I had stabbing pains in my stomach which kept me up all night. I was unable to look after my young children I just felt very low and lousy.

What challenges did you encounter during your treatment journey and how did you manage them?

I underwent my treatment, which lasted for six months and involved taking injections in my stomach and tablets. It was a horrible treatment. I had support from my nurse and children but suffered from mouth and stomach ulcers, fever, bodily aches, and pains. I was incapable of living a normal life and required constant assistance for everyday chores. I was so depressed that I even made an unsuccessful attempt at taking my life. The only thought that then kept me going through the treatment and
severe side effects was the company of my children and praying to Allah that he would gift me a new lease on life.

Could you share any strategies or activities that helped you cope with the emotional challenges of living with hepatitis C?

It took me a very long time to come to terms with having hepatitis C. My faith, religion, and family helped me become emotionally strong. Most of all helping raise awareness, testing, and saving lives became my purpose in life and that helped me become strong.

What is the attitude of the South-Asian community toward hepatitis?

The South Asian community has stigmatised hepatitis due to a lack of education. Socially the South-Asian community cannot accept anything unknown to them and are not willing to learn about, or accept, hepatitis. The community either ignores issues and brushes them under the carpet or makes it a major issue by pointing fingers and making unfounded accusations, which makes people sacred to share information. They associate hepatitis with drug use and extramarital affairs, and they do not like to discuss the possibility of being infected with hepatitis. The community is in denial of hepatitis, and they are unaware of the transmission routes.

How can people in this community share their stories without fear of stigma and discrimination?

Over years of raising awareness in the South-Asian community and distributing information in the relevant languages, and face-to-face conversations with trained staff from the same ethnic background, we have made ground-breaking advances in engagement. Liaising with religious establishments and having them deliver messages to their congregations have started to change perceptions slowly. People are coming forward to access testing at events and have conversations about what hepatitis C is and its transmission routes.

Dealing with stigma and discrimination can be difficult. However, encouraging individuals to share their stories in confidence, with the assurance that their face or personal details will not be disclosed, can empower them and contribute to saving lives through the simple act of sharing their experiences.

Is there a message you would like to share with others living with viral hepatitis?

Be Positive. Get tested and treated. Remember the transmission routes and keep yourself and your loved ones safe.