

## **Cross Party Group on Liver Disease and Liver Cancer**

**“Quality Statement on Liver Disease – a call for action from patients and clinicians at the sharp end of the liver disease crisis”**

**Date/Time:** Thursday 6th October at 1:30pm – 2:30pm

**Location: Virtual (Zoom)** <https://us02web.zoom.us/j/89765692022>

### **Present**

#### Senydd Members

Joel James SM (Chair)

Huw Irranca-Davies MS

Dr Altaf Hussain MS

Ryland Doyle (representing Mike Hedges MS)

#### Secretariat

Lee Gonzalez –

Richard Daniels – Policy and Public Affairs Manager, British Liver Trust

Paul McGlinchey – Policy and Public Affairs Officer, British Liver Trust

Sarah Lowther – Outreach Officer, British Liver Trust

William Williams – patient advocate

#### Clinicians

Andrew Yeoman – Consultant Hepatologist, Aneurin Bevan University Health Board

Kate Pronger – Lead Nurse Specialist Alcohol Care Team, Aneurin Bevan University Health Board

#### Patient advocates

John Bell

Felicity Oppe

Phil Murrey

### **1. Opening remarks from Chair, Joel James MS**

Joel James MS opened the meeting and thanked everyone for joining the second CPG on Liver Disease and Liver Cancer meeting. Joel highlighted that since the inaugural meeting in March, the British Liver Trust's Love Your Liver roadshow visited the Senydd at Roald Dahl Plass on 22 March. 1/3 of members of the Senedd attended the roadshow and many had a FibroScan. Joel stated that there have been 14 questions tabled on liver disease and liver cancer since the CPG was formed, helping raise profile and hold the government to account. Joel said we are still waiting for the publication of the Quality Statement on Liver Disease which has been delayed. And finally, Joel stated that we are seeking to arrange a debate on the liver disease and liver cancer emergency on the floor of the Senedd, so we can raise the profile of liver health in Wales.

### **2. Presentation from Dr Andrew Yeoman, Consultant Hepatologist, Aneurin Bevan University Health Board.**

Dr Andrew Yeoman presented on the challenges and opportunities for tackling variation in liver disease care and outcomes in Wales. He discussed the incidence of liver disease across Wales and highlighted variation across the health boards. Dr Yeoman noted that new diagnosis of cirrhosis currently has a threefold increase in diagnoses every year. Liver disease is becoming more prevalent. In addition, clinicians are getting better at recognising liver disease. Hospital admissions due to alcohol dropped in 2020, and stayed low in 2021. Mortality increased in 2020 and again in 2021. This demonstrates that patients are not being admitted and that it is a complex picture. Since

the covid lockdowns unhealthy behaviours, born in lockdown, have continued and liver disease mortality has increased massively. Data from the liver registry shows that most deprived areas have higher incidence of liver disease than those in less deprived. Primary liver cancer would be expected to follow deprivation in the same way as liver disease. But it doesn't because it is a disease of maturity. Unfortunately the least deprived don't live long enough to develop liver cancer. Other data shows that individuals with liver disease living in deprived areas will die 10 years younger compared to those living in less deprived.

Dr Yeoman went on to discuss what the drivers were in these outcomes. Namely Social, Political and Clinical. Social could include factors such as lower income, lifestyle choices and the inverse care law (those with greatest need for care have least access to care). Political factors could be the obesogenic environment, legislation (such as Minimum Unit Pricing), and healthcare funding. Clinical factors would include the need for early detection pathways. Clinicians need to advocate for the patient's experience and patient voice. The Elimination of Liver Disease in Wales Group (ELDIG) has been working with the British Liver Trust to deliver education. Political factors can be tackled with the help of political colleagues, like Joel James, influencing the legislative and physical environment. Clinical factors would be nailing down diagnostic pathways across Wales and adequate staffing levels.

Dr Yeoman highlighted the National Liver Toolkit. This is an on-line tool of which the majority of use is by GPs and is targeted at GPs. 25% of GPs have looked at it to date. This is a good result to use as a spring board for further collaborative work and education. Currently there are 13.5 whole time equivalent consultants. Of which 8.5 are based in Gwent and Cardiff (South East Wales). Although the numbers have doubled in recent years, we need to double it again to achieve the target of 1 hepatologist for every 120,000 people. Dr Yeoman also highlighted that more specialist nurses are also needed.

### **3. Presentation from patient advocate, Phil (alcohol related liver disease)**

Phil is a 50 years old living in Cardiff. He was diagnosed with cirrhosis (caused by years of problem drinking linked to anxiety, work pressures and more) after an emergency hospital admission in early September 2018. When he was admitted he had collapsed, was confused and had jaundice. Phil needed blood transfusions and invasive tests. And was told he could never drink again. He was later discharged with little more than a dietician sheet and list of AA meetings and very limited awareness of how to manage his condition. Four years earlier, after routine blood tests, a GP told him his "liver was starting to struggle". This was a missed opportunity for earlier diagnosis due to stigma he experienced and the lack of information provided at the time. Phil believes support from the British Liver Trust and alcohol support agencies were essential. Sadly Phil knows others who went back to alcohol and died horrible deaths unnecessarily. Phil stated that GP education is essential to help catch liver disease early.

### **4. Presentation from patient advocate John (hemochromatosis)**

John introduced himself and stated he lives in Flintshire, North Wales. John got his diagnosis when his liver started to fail at the age of 45. John learned that his hemochromatosis condition is genetic. John's father and brother both died of complications related to hemochromatosis. However, John grew up in the care system so was not aware of his risk factors. He had to retire early due to the ill health and felt he had no support or access to information. Discovering the British Liver Trust was a life-line with excellent patient information online and the Liver nurse helpline. Speaking to speciality nurses, who were non judgemental, was reassuring and John also praised the on-line support groups.

John highlighted issues with navigating primary and secondary care and felt it gave him mental health issues. It was challenging to get to see the GP. Most appointments were over the phone. But his GP was reluctant to prescribe due to the cirrhosis. John highlighted that he would often be

referred backwards and forwards between primary (GP) and secondary care (Liver nurse or consultant). There were two years where he was removed from the list for liver cancer surveillance despite being eligible. He concluded his talk with a call to action. He would like to quality statement to commitment to recruitment of hepatologists and nurse specialist so all patients have access to qualified support where ever they live the county.

## **5. Presentation from patient advocate, Felicity (Liver Cancer)**

Felicity is a 65 years old and living in Cardiff who faced a shock diagnosis of Hepatitis C and liver cancer last December. She feels this shows liver disease can affect anyone. Felicity stated that in her teens she had experimented with drugs and believes the Hepatitis C exposure to have occurred in this period. There were missed opportunities for early diagnosis over the years. Felicity has had Gall bladder and hernia operations along with symptoms of liver disease that went undiagnosed. Felicity had a number of consultations with her GP over the years – in retrospect with early signs of liver disease. Instead of taking this seriously the GP would question whether she had had a Greggs or a drink over the weekend. Felicity stated that the Health Professionals assumed her condition was due to alcohol use. Eventually additional blood screening for Hepatitis was made. Felicity stated she is aware of people who have waiting 16 months for hepatitis tests. And that patients have to take the initiative rather than some form of screening. Felicity highlighted that she was asymptomatic for 20/30 years. Felicity stated that early detection and tackling stigma is key. She emphasised that we are not going to change early diagnosis without assumptions removed from of health professionals. Finally, Felicity stated that 30% people with liver cancer live for 5 years or more and she hopes to be one of these.

## **6. Kate Pronger, Lead Nurse Alcohol Care Team**

Kate spoke about the impact of expanding alcohol support services within Aneurin Bevan University Health Board (ABUHB). Expanding service provision to 7 days had a significant impact in tackling harmful drinking behaviours, increasing referrals and assessments (i.e. 10-12 every weekend) and improving health outcomes, particularly among those most at risk of developing severe alcohol related liver disease. This reflects missed opportunities for earlier diagnosis where service provision is more limited. Transient elastography is also being piloted (Fibroscan) to improve earlier detection of liver disease. Kate hopes that all health boards in Wales will have the opportunity to have such a service.

## **7. Questions and Answers**

Dr Altaf Hussain MS. Altaf Hussain raised concerns around the lack of understanding of alcohol related brain damage and liver damage and the importance of education. He stated that training of GP's could be improved.

Dr Yeoman agreed with the statement. He highlighted that the testimony of Phil and John speaks to that inconsistency of care provision. He stated that we need to work collaboratively with primary care and improve cross-departmental communication.

Huw Irena Davies MS thanked to the patients for sharing powerful testimonies. He asked Dr Yeoman about correlations between the increase renal dialysis and liver disease.

Dr Yeoman stated that risk factors drive other health behaviours too. There is an avenue of opportunity to be responsive to cross cutting areas – an opportunity to improve support for primary care in these areas in tandem with wider policy, societal and clinical influencing.

Altaf Hussain MS noted that the diagnosis and treatment of Hepatitis C is often complex, exacerbated by the backlog.

Dr Yeoman stated that he is not aware of a backlog for testing for Hepatitis C but reiterated the importance of health professionals providing testing in community settings.

#### **8. Closing remarks from Chair, Joel James MS**

Joel James MS thanked everyone for their contribution. He thanked the patient advocates in particular for sharing powerful testimonies and calls for action. Joel also gave thanks to Kate Pronger and Dr Andrew Yeoman for providing a clinical perspective and informing our thinking around policy messaging ahead of the forthcoming debate on liver disease and liver cancer. Joel concluded his remarks by thanking Members of the Senedd for their support and providing an overview of action points.

#### **Action Points**

- Joel James MS to seek a debate on liver disease in the Senedd in November
- CPG to write to the Minister on the delayed Quality Statement on Liver Disease and priorities for action to improve early detection, treatment outcomes and care for liver disease
- Secretariat to provide tailored Parliamentary Questions with Members of the Senedd
- The next CPG meeting is tentatively scheduled for the first quarter of 2023
  
- The Love Your Liver roadshow will be back at the Senedd next year on 14 March 2023

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