

## Appendix 2. PBC impact on social well-being

Social Well-Being Domain	Impact
Relationships	<p><b>Impact on patients' relationships with family and friends</b>            Diagnosis brought them closer to loved ones, but loss of contact with friends who did not support them through their experience.            Greater appreciation of the time with loved ones after diagnosis</p> <p><b>Impact of feeling overwhelmed by treatment</b>            Resulted in implications on relationships with those closer to them</p> <p><b>Additional caring responsibilities for partners</b>            Challenges in managing day to day tasks with restricted mobility was difficult for both patients and their partners, particularly when the main carer had additional caring responsibilities: <i>"my wife and kids, it's affected them a lot more (...) I don't get anybody else to look after me. It's only my wife who has to do it so, there's a lot of little things which is time, energy consuming and extra load on their work as well"</i>.</p> <p><b>Challenge of disclosing diagnosis to others</b>            At the end of treatment interaction with new friends, romantic partners, and co-workers was challenged by the decision to disclose their diagnosis (particularly in young adults): <i>"I feel it's very isolating because for me it was such a personal experience that I find it hard to share with people"</i></p> <p><b>Sexuality, fertility and intimacy</b>  <u>Patients without partners (mainly patients aged 20-30 years old)</u></p> <ul style="list-style-type: none"> <li>- Difficulty in establishing intimate relationships: altered body image and side-effects of treatment: <i>"I just accept no woman would really have any interest in me"</i></li> <li>- Infertility and the need to consider alternative methods of conception: <i>"when you're dating, when is an acceptable time to tell a girl that you're infertile?"</i>.</li> </ul> <p><u>Patients with partners</u></p> <ul style="list-style-type: none"> <li>- Brought couples closer together</li> <li>- If there was an impact of PBC on sexuality it was limited to the treatment phase: <i>"Unfortunately, that can't happen at the moment. One of the side-effects of one of the pills I'm on is actually erectile dysfunction"</i></li> <li>- Adaptation in sexual practices to accommodate changed bodies</li> </ul> <p><u>Older patients (patients aged 61 or older)</u></p> <ul style="list-style-type: none"> <li>- Adopted other forms of intimacy e.g. by cuddling and supporting each other</li> </ul>

- *"I mean, our sexuality had gone some good time ago to be honest, so it's not really affected that but we're still a close couple"*
- Impact of having an amputation on sex life long after the end of treatment. *"I think that's more of a mind thing from my point of view, because obviously in bed, I don't wear my prosthesis (...) we don't really discuss it"*

School/University/  
Work

### **Teenagers and young adults**

Being in hospital disrupted school/university life: *"I haven't been to school for three months now"*.

Returning to school showed this to be an important sign of regaining normality but depended on the way teachers handled changes in physical abilities. Phased return to school/university and support available was critical.

Feelings of insecurity because of lack of experience in the workplace and the uncertainty of being new in a job: *"I was really concerned with obviously starting a new job, the implications of this illness when I'd just started. I didn't know regarding sick pay and things like that, and whether they might just get rid of me"*

### **Adults**

Some patients had their jobs secured for the time they were going through treatment or they were already retired  
Some patients opted for early retirement or had to reduce their working hours due to fatigue or physical impairment

Most patients had a phased return to work due to fatigue and mobility restrictions, as well as the emotional strain of having PBC, but the options were limited for patients who owned their business or worked as freelancers

For some patients the physical limitations/restrictions imposed by treatment/surgery led to a career change or redefinition of career aspirations: *"I had to decide to do something else, something which I could do, something where I could improve and where my [physical] situation wouldn't affect my career so badly"*

### **Financial impact**

The experiences were a result of a combination of financial support available and the possibility to either return to work or find an alternative carer pathway

- type of employment contract, size of the company, availability of health insurance and personal savings or family financial support available had an impact on financial wellbeing
- When the consequences of treatment were so pervasive, patients were not able to work, had no access to family support or savings, and had to access benefits, this had a negative impact on their financial well-being: *"The effect it's had on me is I can't afford to go out anywhere. I can't afford to buy myself anything (...) people don't understand how tight things can be financially"*.

Participation in  
leisure activities

**Impact of pain**

Managing pain whilst trying to take part in the activities they enjoyed was a challenge

- e.g., following limb sparing surgery a patient described how he endured the pain and restrictions imposed by it: *“I do go to [activity], but I do experience extreme pain after”*

**Impact of fatigue**

Fatigue and lack of energy were experienced long after the initial treatment phase

Patients identified triggers and managed their day to accommodate it, but the reality was that fatigue had a profound effect on their participation in social activities, work and school performance, as well as affecting emotional well-being: *“I’m careful about not pushing myself too much, but also it’s quite unpredictable really. I know that if I do a lot then I will pay for it (...) I just allow myself to cancel plans and go to bed”.*