

Date of interview: 30 July 2010

Duration: 40:00

Participant: SU

1. Ok. So this is my first picture..

2. He's in a lot of pain, on his face

3. You can tell?

4. And his back, yeah

5. So what can you see in his face?

6. Anger.

7. Anger.

8. He's in pain.

9. Yeah, so how can you tell? How can you tell he's in pain? What is it about him?

10. Coz he's holding his.

11. Coz he's holding it.

12. Side, yeah.

13. Yeah ok. Say you might be feeling angry, what can you do about that?

14. Take some painkillers and if it's really bad go to the doctors.

15. Yeah ok. Anything else you can do?

16. Lay down.

17. Lay down? Yeah ok. So you can try laying down, taking painkillers, going to the doctors. How bad do you think his pain is?

18. By his face he's in a lot of pain.

19. Yeah? So from this scale that I sometimes show people, its what we call a pain scale, so here we've got no pain at all and it goes all the way up to 10, which is like the worst pain you've ever been in. how bad do you think his looks?

20. About 8.

21. 8? So a lot of pain?

22. Yeah.

23. Yeah. Ok. How can he get help then?

24. Go to the doctor's surgery, like a walk in clinic

25. Ok so a doctors walk in surgery. So who would know he's in pain?

26. Well, he is holding side, he's in a lot of pain

27. So you think people could see it?

28. Yeah.

29. You think other people could see? So if he was here you think other staff would be able to see?

30. Yeah.

31. Ok. if you were this guy and you had a back pain like that what would you do?

32. I don't know, it's terrible to be in a lot of pain

33. Yeah yeah. But what would you ask for?

34. I'd ask for some pain killers or to go see the doctors

35. Yeah ok. What do you think the staff would do if this guy told the staff?

36. Try talking I suppose

37. Yeah call the doctor? Ok, lovely... Do you ever get a back pain?

38. Yeah.

39. You do?

40. Like sleeping in bed.

41. In bed? So is it when you wake up in the morning?

42. Yeah.

43. Yeah ok. Can you describe kind of what its like? That pain?

44. Terrible pain.

45. What does it feel like?

46. Sharp pain sometimes.

Comment [L1]: Abstract pain sign

Comment [L2]: Location of pain

Comment [L3]: Emotion

Comment [L4]: Sign of pain

Comment [L5]: Strategies for pain

Comment [L6]: Strategy

Comment [L7]: Sign of pain

Comment [L8]: Pain severity

Comment [L9]: Get help

Comment [L10]: Sign

Comment [L11]: Negative connotations

Comment [L12]: Strategies for pain

Comment [L13]: Talk to the person – her past experience?

Comment [L14]: Cause of pain?

Comment [L15]: Description - negative

Comment [L16]: Sensation

47. Sharp pains.
48. My legs sometimes.. sharp pains.. sharp..
49. And is it at the bottom of your back?
50. Yeah in the spine.
51. Right at the bottom of your spine... do you know why you get that?
52. No coz I had a, two operations.. they took my disc out of this one first, but they left a big hole so they had to do it again. In my neck
53. So you had another one in your neck?
54. Yeah, and there...
55. So you think that's related to your back pain you get? And when you get that do you let anyone know?
56. Nah.
57. You don't let anyone know?
58. No.
59. Why is that do you think?
60. Coz they don't take no notice of me
61. Right, so you don't think they take notice. So there have been times and no one took any notice..?
62. Yeah.
63. Yeah? Quite a lot?
64. Yeah.
65. What tends to happen when you say you're in pain?
66. They just say you've got to wait, you've had some painkillers
67. So they give you some but do you feel like the painkillers..
68. They're not touching the pain you know what I mean
69. Do you know what ones they give you?
70. Panadol.
71. Ok.
72. Little white tablet.
73. Do you think they're strong ones?
74. Ones supposed to, tremordols' strong. I had that once
75. What that any good?
76. No.
77. Ok, you're back pain that you get, is it every day would you say?
78. Yeah when I get out of bed coz this is a..
79. It's a special mattress?
80. It's like you're laying on water, coz it's like, really hard.
81. Yeah is it not very comfy?
82. No it ain't.
83. Have you let people know that it isn't very comfy?
84. Yeah I let the manager know but I don't get nowhere with her. They were meant to get me a hospital bed but the man that deals with all the sorting out is on holiday.
85. Right, but you're hoping to get a different bed, coz did you ever have back pain before, coz you said you'd been here a year... in your previous bed?
86. Yeah, loads of pain.
87. Yeah. Ok and the back pain you get, how bad would you say it is?
88. Sometimes its really bad, especially when I sit in this wheel chair, it's really bad. On my spine. But you've got to learn to live with it they say.
89. Where have you heard that?
90. Some of the nurses.
91. That what they say?
92. Yeah.
93. What do you think of that?

Comment [L17]: Location

Comment [L18]: Cause of problem?

Comment [L19]: Does not tell of pain

Comment [L20]: Past experience – ignored

Comment [L21]: Other's response - wait

Comment [L22]: Painkillers not helpful

Comment [L23]: Different degrees of pain meds

Comment [L24]: Meds unhelpful

Comment [L25]: Cause/time of pain

Comment [L26]: Tell others

Comment [L27]: Severity

Comment [L28]: Negative connotations

Comment [L29]: Location

Comment [L30]: Coping strategy suggested by nurses??

94. I don't think so. No one should have to live in pain. Really bad pain

95. *So it sounds like they're saying that people should just live with being in pain*

96. Yeah and they've got their favourites who they want to help, but I'm not one of them

97. *That's how you feel?*

98. Yeah.

99. *So in terms of the pain you get in your back, you've let people know here, you sometimes have painkillers, is there anything else you try to make it better?*

100. Well they gave me arthritis gel but they've stopped it. So really I get nothing on it, I mean if I go out and buy it myself.

101. *So why did they stop that?*

102. X did it.

103. *So have you got arthritis?*

104. Yeah, in the knees, hand.

105. *Did you ever put that on your back?*

106. Yeah sometimes.

107. *Yeah but they've stopped it. Are you expected to go buy it if you want it?*

108. If I want it I go buy it tomorrow with my son.

109. *Is it like ibuprofen gel yeah? And does that help?*

110. A little bit. But I've got a load of fluid in me legs, they're rock hard and that's what's killing me. That's why I can't walk properly, not gonna try it and fall over

111. *Yeah, and is that causing you a lot of pain?*

112. Yeah.

113. *Yeah. I wonder, whether you'd like to talk a little bit more about your legs or whether we can come back to it if we look at a couple more pictures. What would you like to do? Would you like to look at more pictures or talk about your leg pain?*

114. My leg pains murder, it doesn't go away, its non-stop hurting me. There must be something they could do for the fluid. Or water tablets, as soon as they give me I'm on the toilet.

115. *Right. So they've tried water tablets.. and how long have you had that pain in your legs?*

116. Quite a long time, a year at least. It's got worse since I been in here. I know my legs wobble and that at the other flat but not as bad as this.

117. *Can you describe what the pain in your legs is like?*

118. Like a knife sticking in them

119. *So it's very sharp?*

120. Yeah.

121. *Yeah and is it all the time?*

122. Yeah.

123. *And you said you took water tablets?*

124. I take them, they give them to me, 3 in the morning, and 1 at dinner.

125. *And that's supposed to help with the water retention..*

126. Yeah but it's not helping .

127. *No and do they give you any painkillers for it?*

128. Yeah, paracetamol.. Tramadol and this other little strong one but they don't give it me when I need it.

129. *Right, so they give it to you what once a day?*

130. When I ask for it...

131. *So when you ask for it. And do you let them know when you're legs are hurting?*

132. Yeah.

133. *Yeah and what do staff generally say?*

134. Well this one that's on today she doesn't like me, she just lets me sit and suffer, don't she P (referring to son), and it's wrong.

135. *And have you let anyone know about how you feel about.. About the different staff here?*

Comment [L31]: Attitude to pain

Comment [L32]: Negative connotations

Comment [L33]: Perceptions of staff as not helping her with pain

Comment [L34]: Cause of pain

Comment [L35]: Lack of support in pain relief?

Comment [L36]: Location

Comment [L37]: Helps a little

Comment [L38]: Mobility difficulties

Comment [L39]: Strong negative connotations

Comment [L40]: What can be done? Must be something

Comment [L41]: Duration

Comment [L42]: Worsened

Comment [L43]: Imagery / sensation

Comment [L44]: Constant pain

Comment [L45]: Painkillers not helping

Comment [L46]: Requests painkillers

Comment [L47]: Access to meds is problematic for her

136. Yeah but they don't take no notice, they think it's all in me head, like this dripping water. I was told it was nerve damage by my own GP my matron I used to have, and it's getting worse and that doctor out there sent the psychiatrist to see me, they think it's all up here.

Comment [L48]: Response from others when in pain – ignored, disbelief

Comment [L49]: Cause of pain

137. So the feeling...

138. It really drips in my. In the side of my face. Out me nose.

Comment [L50]: Sensation

139. So you can feel it?

140. Out me nose in me throat, and it won't stop me coughing when I lay down and its even coming out me eyes.

141. So you said they sent the psychiatrist.

142. They sent the psychiatrist before Christmas then they sent a psychologist. And I don't think that's helping me.

143. What is it that you'd like? What would help?

144. Well just see what the real reason it's happening. that's all I'm saying. They might be able to do a scan on my brain.

Comment [L51]: Cause desired

Comment [L52]: Investigations wanted

145. So you'd like a scan?

146. Yeah.

147. And if you asked for that...

148. No that's what I was gonna ask them today for they're still out there yapping.

149. So you're quite anxious to see him?

150. That's if he sees me.

151. Well if he does we can stop this and I can wait outside until you're finished. Ok. So do you no why you get those pains in your legs, why you get that water retention? Has anyone ever explained to you?

152. No, nothing, they keep saying is I got to learn to walk with me frame, and I gotta put my feet, but I do that but it don't go away, the pains still there

Comment [L53]: Pain still present with strategies in place

153. And do the doctors ever discuss with you about your pain?

154. No.

155. Do they ask if you're in pain?

156. Well the nurses tell them coz I told them I'm in a lot of pain.

Comment [L54]: Tells others of pain

157. So the nurses let the doctors no you're in pain and how does the doctor respond?

158. Sometimes he comes in, sometimes he just says no.

Comment [L55]: Refusal to be seen by Doctor

159. Why do you think he comes to see you? Or why do you think he says no? what makes him decide do you think?

160. Dunno.

161. It sounds like there are staff here you have quite a difficult time with, there's some here that you like.. ok.

(interrupted)

162. Ok, well I've got another picture to show you, if you wanna have a look at that one fore me

163. Looks like she's got a splitting headache.

Comment [L56]: Description, location

164. Yeah how can you tell?

165. Coz she's holding her head like that.

Comment [L57]: Sign of pain

166. Who could tell do you think that she has a headache?

167. Her family?

Comment [L58]: Could tell others

168. What do you think they'd notice?

169. Her holding her head.

Comment [L59]: Others would see pain sign

170. So how might she be feeling?

171. Bit sad.

Comment [L60]: Emotion

172. Bit sad you think? How bad does her pain look? Do you remember we said 0 to 10?

173. It's about 7.

Comment [L61]: Severity

174. ?? So it's hurting quite a lot ok, so what can she do about it

175. Have a couple of tablets. Go to the chemists and ask them.

Comment [L62]: Strategy – painkillers, chemist

176. Yeah what do you think they'd suggest.

177. Depends on how bad it is...

Comment [L63]: Strategy depends on pain severity

178. Do you think they'll suggest tablets?

179. Well they might say one of them cooling packs on her forehead.

Comment [L64]: Alternative strategy for pain

180. Have you tried them?

181. Yeah.

182. What do you think of them?

183. They're alright.

184. Ok, so she could go get some tablets, go to the chemists, could she let anyone know do you think?

185. Well, her family. Or whatever.

Comment [L65]: Tell others

186. She could let them know ok, and how could she find out what's wrong?

Comment [L66]: Consult HCP

187. Go see a doctor.

188. What do you think they'd do?

189. Listen to her.

190. Yeah so they'd listen to her and let them no she's in pain. What could a doctor do about a headache?

191. Well she might be migraine and they'd have to give her treatment

Comment [L67]: Possible cause and treatment

192. Right so they could give her migraine treatment. How would they know if it's a migraine or a headache?

193. Blood tests.

Comment [L68]: Investigation

194. Ok so they could do a blood test. could they do anything else?

195. No.

196. Ok, so do blood test, lovely. Have you ever had a headache like that? Sounds like you have

197. Yeah, I have one now!

Comment [L69]: Currently in pain with headache

198. You have one now? Oh dear... do you get those a lot?

199. Yeah.

200. You do?

201. Yeah.

202. And what do you tend to do when you've got them?

203. Well I just have to sit and wait till it's time for my painkillers.

Comment [L70]: Sense of helplessness? Sit and wait for meds that do not help much

204. Right and you said you'd tried those cooling gel things as well.. so do you get them would you say every day?

205. Nearly every day yeah.

Comment [L71]: Frequency of pain

206. Gosh and how bad do they get?

207. Really bad. I'm in pain I get really miserable and angry.

Comment [L72]: Description

208. So it sounds like you've got lots of different pains in different places and yeah I think your right, they do affect our mood and how we feel. Would you say you're feeling pretty miserable at the moment?

Comment [L73]: Emotional impact

209. Yeah.

210. Yeah. I mean is it ok for us to be talking about this stuff?

211. Yeah.

212. Yeah? It's ok.. ok. And when you've got a headache do you let people know?

213. Sometimes I do but I think it's not worth it, especially this nurse that's on. Shed just ignore me, let me suffer. But it's not right. Coz I used to be in room X but I moved down here and since I moved its all changed, they don't wanna no. And I'm still the same person! Just coz I've changed rooms

Comment [L74]: Given up telling others? Reluctant to say based on past experience of being ignored

214. So why did you change rooms?

215. Well.. there's a man next door to me, he kept lying about me but they took his side and I was told either move room or find another home but they don't say it to him. he said I called him a Jew, but I didn't coz I was at my cousins wedding on that day.

216. So there's a lot of friction with that man?

217. Yeah.

218. But you feel that since you moved rooms.

219. But he's still coming round the back here just to torment me, to see if I say anything to him, they think I'm stupid but I shut me ears to it.

220. *But its sounds like things are difficult with some of the staff as well.*

221. Yeah especially that one.

222. *And how they respond to your pain.*

223. They **don't** take no notice of my pain, he's not coming tomorrow he's gone down the corridor, he's gone now.

224. *So do you sometimes, it sounds like sometimes if you are in pain you don't let people know?*

225. No coz what's the **point** if you don't get nowhere.

226. *So you feel there's not much point to it?*

227. No.

228. *Ok. Do you think we could have a look at one more picture?*

229. Yeah, together.

230. *This is my last picture.*

231. He's **hurt** his hand.

232. *He's hurt his hand?*

233. Yeah on some nails, so he's in pain.

234. *Yeah, so how might he be feeling?*

235. **Sad**.

236. *Does he look sad do you think?*

237. Yeah, he's **crying** isn't he.

238. *So he might be feeling sad, I mean how bad do you think his pain is?*

239. About **8**.

240. *About an 8? So he's in lots of pain. How else can you tell he's in pain? You said you could see his hand...*

241. His face.

242. *What can you see in his face?*

243. His teeth **are** showing, his face is screwed up.

244. *Right and so that looks like he's in pain. Yeah, so who could tell that he's in pain?*

245. **His** mum!

246. *His mum could tell. and would she notice the same things that you noticed do you think?*

247. Yeah I think so.

248. *Yeah ok, what could he do about it?*

249. Contact **his** mum.

250. *What would she do, do you think?*

251. Well if it's too **bad** shed take him to the doctor or the nurse

252. *And what do you think they'd do?*

253. They'd **dress** it.

254. *They'd dress it.. yeah yeah would they give him any tablets?*

255. Pain **tablets**.

256. *Pain tablets, yeah ok. So do you think it would be obvious what's wrong with him?*

257. Yeah.

258. *Do you think it's obvious from the picture what's wrong?*

259. Yeah.

260. *Yeah. What do you thinks wrong?*

261. He's in pain of his **hand**.

262. *In pain with his hand.. ok.. so if you were this man what would you do?*

263. (long pause) if that was me, uh, I'd just go **to** the doctors.

264. *Ok so you'd go to the doctors.*

265. See a **nurse** or someone. If I couldn't see a doctor. Like they're not seeing me today either.

266. *Right, what time do you finish? Or does.. does he come for a certain time?*

267. Yeah.

Comment [L75]: Feels ignored when in pain

Comment [L76]: Futility of reporting pain. Learned behaviour.

Comment [L77]: Location

Comment [L78]: Emotion

Comment [L79]: Sign

Comment [L80]: Severity

Comment [L81]: Sign - facial

Comment [L82]: Mum can tell he is in pain

Comment [L83]: Let others know about pain

Comment [L84]: Strategy depends on severity of pain

Comment [L85]: Treatment

Comment [L86]: Treatment with meds

Comment [L87]: Location

Comment [L88]: Strategy – consult HCP

Comment [L89]: Second strategy – consult nurse

268. Yeah. Have you ever had a pain like that?

269. Yeah. I went up on a 28... 25 bus, got off at X and I was coming down the steps and the bus jolted and I broke **that** bone there. And the pain of it all swelled up **like** knives going to hospital and they wanted to operate but I couldn't let them coz I had no one to look after my son. So they just put it in plaster

Comment [L90]: Cause of pain – accident/injury

Comment [L91]: Imagery

270. And did it heal ok?

271. Yeah. Still gives me **trouble** now and again, especially when I'm bending. (yelps) and that's not **good** enough.

Comment [L92]: Colloquialism for pain

272. Do you want to let someone know? Do you want to speak to someone about it?

Comment [L93]: Dissatisfied – should be pain free?

273. Yeah.

274. Yeah. Do you want to talk to someone now about it and we can finish this in a bit?

275. No we can finish this first.

276. Ok. So you said you'd hurt your hand on the bus,

277. Yeah broke, **fractured** that bone.

Comment [L94]: Cause of pain

278. Can you remember what that was like?

279. Yeah, **terrible**, pain.

Comment [L95]: Negative connotations

[interrupted]

280. She came and told me this time.

281. So she came and told you.

282. Yeah, he's gonna see me Tuesday.

283. Yeah, and how you feeling about that?

284. Alright, if he keeps coming to work. And that's only two days I went where did I go for surgery (pause) last Tuesday I went to surgery, so its not Tuesday Wednesday Thursday Friday, 4 days not two. Coz I wanted to have me hair done but I couldn't go coz they were waiting for appointment. Coz the ones that in charge of the practice owns it and he's leaving next Friday

285. Right, Ok. so where were we.. we were talking about your hand weren't we? And you said it was terrible?

286. Well it still gives me **jack**, and sometimes, I know I've got **arthritis** in it, but I can't bend my fingers and when I grip things I drop 'em. Coz I had to go into a day care hospital and they cut it bad, they're supposed to done it again but they never **bothered**

Comment [L96]: Colloquialism

Comment [L97]: Cause of pain

Comment [L98]: Sense of others as not bothered about her and her pains

287. So is it something to do with the muscle there then?

288. The **nerve**.

Comment [L99]: Cause of pain

289. The nerve? Yeah

290. That was really broken, they stuck in it plaster but they put the wrong **plaster** on, I had to get it cut off coz a scratch scratch scratch it was.

Comment [L100]: Problem with HC service received?

291. But it still gives you pain does it?

292. Yeah **every** now and then down here.

Comment [L101]: Frequency of pain

293. What's that like? Is it a sharp pain? Or is it different?

294. Its **sharp**.

Comment [L102]: Description of sensation

295. It's a sharp pain as well.. And what do you do when you've got that pain

296. I just try to **shut** it off best I can but sometimes you can't shut it off

Comment [L103]: Strategy – ignore the pain. Does not always work.

297. Yeah.. Does it last a long time?

298. Yeah.

299. Yeah, So you try to shut it off? How do you try? What would you do? To try and shut it off..

300. Watch **the** telly. But this afternoon I got.. do you know X from X she's a psychologist, the head one.

Comment [L104]: Strategy - distraction

301. X? Yeah

302. Yeah, She's coming to see me this afternoon.

303. Oh is she?

304. At 430. But X finished half past 3 so I can go up seaside it is, I can go down there for a little while. I don't want to feel shut in my room all the time. I used to do that at home, I couldn't go out, I don't want that here, the only time I go in the trees.

305. Why do you feel like you don't go out?

306. Coz I can't push myself in the road.

307. Right, so it's hard to push yourself?

308. Yeah.

309. So you feel you have to have your son to push you along?

310. Yeah.

311. But X is coming to see you?

312. Yeah bout 4 to half past she said.

313. Ok. So we talked a little bit about your arthritis haven't we?

314. Yeah.

315. And we talked about your fluid in your legs, I mean, is it ok for me to ask what health conditions do you have?

316. I've got bad heart, they thought it was me kidneys but I went along to hospital with it and they said your kidneys are alright it's your heart. Now when I push myself it's still a strain on my.. but umm they're supposed to be getting me electric battery. On the side of this chair but it's not gonna make me a load of difference coz I can't go out in the street on me own if I had an electric wheelchair I could just take myself out when I feel like it, even if it's only to the corner shop

317. So that's not what they're gonna give you?

318. No.

(interrupted)

319. So you said about, you've got some problems with your heart, your chest?

320. Yeah

321. Do you know what the name of that is?

322. No, I want a heart tablet at night. I know they're trying their best, but when you're depressed, everything seems to get you down. Like I've got an ulcer on my foot and all this green stuff was coming out of it, it's only like a little bit big but it wont go. Its terrible when you're in pain, I've got me feet, me legs, me knees, my arm, my shoulder, everywhere else, me head. Terrible pain.

323. You've got lots of different pains.. it sounds like they always seem to be there?

324. Yeah, they're non-stop they never go away. But I was told yesterday by this X, do you know X from carers and (unclear) and she really showed me up you know, and it really hurt that's she discussing me without me being there but I come out there and listen coz I've got the right to be there but I don't make up things, this is happening to me.

325. So you feel like people.. people feel like you're making..

326. Yeah they think its all in my head, they think I'm making it up but I'm not... I just wish every (unclear)

327. It sounds like that's a big worry for you..

328. Yeah.

329. Yeah. Do you think they've talked about all your different pains?

330. Yeah.

331. Ok, and I want to ask then, is it ok if I ask a member of staff here what you're health conditions are, and I'll tell you for why. It's because as part of what I'm doing, it's good to know what health problems people have to see if how much pain they're in is related. So it's good to know the technical names for things. Is there anyone in particular I should ask?

332. X.

333. So I'll ask her to let me know coz I don't want you to think I'm talking behind your back or anything.. ok.. I've got a few questions now just to finish off about pain in general. Not specifically do to with you. Just to kind of, just trying to find out what people know about pain.. can you tell me what pain is?

334. Yeah.

335. What is it?

336. Sometimes it can be a shooting pain.. pain like, needles going through your body.. electric going through your body..

Comment [L105]: Mobility problems

Comment [L106]: Negative connotations

Comment [L107]: Various locations of pain

Comment [L108]: Constant pain

Comment [L109]: Emotional pain

Comment [L110]: Genuineness brought into question – disbelief by others

Comment [L111]: Disbelief

Comment [L112]: Pain sensation

Comment [L113]: Imagery

Comment [L114]: Imagery

337. *Mm, and why does it, why do we get that? Why does it feel like that?*

338. Dunno.

339. *So you're not sure why its there but you can describe what it is.. it might sound like an obvious question but what is bad about pain? What 's not nice about it?*

340. Well there's nothing nice about being in pain. It makes you really irritable and depressed.

341. *Right, so it affects you.. is there anything else bad about it?*

342. No.

343. *Where can we get pains?*

344. The stomach, head, ears, neck, I got pain in my arms, think it's a way, you cant lie on your side in that bed.

345. *Yeah, coz it looks a bit boosted up, lots of cushions*

346. Yeah it's a specially electric bed that pumps up for people with bad legs but it don't help me coz there's no safety guard on it.

347. *So there's no rail? Have you ever fallen out?*

348. Nearly. That's why I'm frightened. I'd really hurt myself.

349. *Have you asked for a rail?*

350. No.

351. *Do you think you could?*

352. Well I could ask X later.

353. *Do other people have rails?*

354. Some of them may yeah. I did ask people when the manager was called X, I asked him but nothing come of it.

355. *So you said we can get pains in lots of different places when do we get pain? When does pain happen?*

356. Dunno. When it wants to come.

357. *When it wants to come? So when can that be?*

358. When you're walking, you can't say that bout me but if you got something, like I've got fluid pain comes then.

359. *Are there any other times? You said walking.. and if you've got problem like fluid in the legs..*

360. Yeah or arthritis.

361. *Yeah so it can come through that..ok.. what causes pain?*

362. Pressure.

363. Pressure.

364. Yeah.

365. *So where is the pressure?*

366. In my knees.

367. *Right so in the knees, that can cause pain, what about say your headache?*

368. Well I have got a headache.

369. Yeah..

370. I don't know what's doing it..

371. *So what causes that pain, you're not sure?*

372. No.

373. *Ok, what can make pain less?*

374. Take a couple of Tablets. Or get one of those beds.. lay down on the bed but the I can't get up by myself.

375. *Yeah, so there are things that can make pain less.. can you think of anything else?*

376. I can't think straight.

377. *Ok well finish soon. What makes pain worse?*

378. When I sit about..

379. *Sitting about?*

380. Yeah. In this chair..

381. *Yeah so that makes your pain worse?*

Comment [L115]: Pain is not nice

Comment [L116]: Emotional impact of pain recognised

Comment [L117]: Locations of pain

Comment [L118]: Pain restricts mobility

Comment [L119]: Cause

Comment [L120]: Current pain

Comment [L121]: Cause of pain unclear

Comment [L122]: Strategy – meds, special bed

Comment [L123]: Exacerbates pain

382. Yeah sometimes, or, I mean we have an exercise man he's due next Friday morning.. and if I try to do the **exercise** and join in, sometimes I can't do some of them.

Comment [L124]: Strategy - exercise

383. *Does that cause pain? That causes pain sometimes.. so being in your chair and doing exercise sometimes can make pain worse.. is there anything else that can make it worse? They're the main two.. yeah. If you're in pain what are your options? What can you do?*

384. Ask the nurse for a couple of **painkillers** or **pop your feet up**, or **lie on your bed**. That's all I have to say.

Comment [L125]: Tell others, request painkillers, rest limbs

385. *Ok have you got any other ideas yourself?*

386. No.

387. *Ok. If you had a friend who told you they were in pain what would you say to them?*

388. Go take and take a **couple** of tablets and if that don't work come and book an appointment at the doctors.

Comment [L126]: Strategy – meds, HCP

389. *Ok, how can people find out more about pain? If people want to learn about pain, how they can find out more?*

390. Well you can buy **booklets** about pain. At the chemists shops.

Comment [L127]: Info about pain can be sourced

391. *Is there any other way you could learn?*

392. No.

393. *Ok, do you feel like you know a lot about pain?*

394. I do.

395. *Yeah ok, so thank you for that, were kind of finished now. How did you find talking about this?*

396. Alright.

Date of interview: 18 August 2010

Duration: 55 mins

Participant: (parent)

1. Could you tell me about a time when you remember S being in pain and it was quite obvious that she was in pain?

2. Well the easiest one that I can tell you is the time when S is having her period.

3. Alright, yeah.

4. Especially at the month of them you know, then she's very very, you know, like, very in pain and to know, to find out if S is in pain it's very difficult for me but maybe because I'm her mother, that I've been living with her for all these years, so it's like, I guess things from her like when she's in pain, I see from her face and what I always do is I touch her body and see if stuff here hurts and because S doesn't have any understanding of no and yes or any word like no or yes and sometimes what I find is that when I touch her somewhere that is painful then she pushes me up. She takes my hands off from her.

5. So does she communicate verbally?

6. No

7. Ok so you'll kind of look to her face or how she pushes you away?

8. Yes, yeah.

9. What do you notice in her face when she's in pain?

10. She'll usually bite her mouth. She doesn't want you to look up, she doesn't want you to keep an eye contact or make it an issue. You know, she does that and sometimes she'll hide herself in her room, so like, as I said, 'cos I've been with her all the time that, you know, so I always get tense and so I like giving her like a painkiller or like hot water bottles, like hot water, as my mum used to do with me when I was younger, to, you know, put it there and I was communicating with the centre that she goes to, and I say oh S isn't looking very normal, you know, leave her or don't let her do.. Or tell her to do something that she doesn't want to do because sometimes she doesn't want to come out at all. And if you go to her room she pushes you back and she'll push the door on you and you can see her sitting down quietly and sometimes tears will drop out. That's the one I don't like, that's when I get really, really down when I see her tears.

11. Yeah she's crying.

12. Yeah when she's crying then I know that she's very, very in pain. But thank god we just had, for the past about 5 years now we have a new doctor, she's a lady doctor so she understands a bit. So anytime when I find out any little difference or chance that S is not very comfortable or S is a bit funny she is always asking to bring her and she says to me now "tell me how she is?" or sometimes when I take her she doesn't want to even go in the room to see her then maybe Dr.L will let her sit down and we go to the little small room and she will come to her and talk to her and talk to her and maybe a smile will come from her face and she'll maybe say let's try this on her and everything will be alright, if not just bring her back. Like this woman now they have trying for the last three years, they don't know exactly, but she's been coughing coughing coughing and I was in such a stressful way because S can't say "oh mum its chest pain" or whatever so that the language was, the GP was trying a lot of different ways. A cough mixture, antibiotics, we try all sorts of ways. So last year they sent us to [Place] to have like a chest S-ray and because S wouldn't stay still for them, because you have to breathe in and hold the breath in before they can you know, it didn't work. We were there for about an hour on and on they were trying put a jacket on, they need to stand on the back to do it with her and with me it didn't work but the nurse said they would try and see whatever they did get and guess, whatever..

13. Yeah they didn't see anything from it.

14. Yeah they couldn't see anything from it, I wasn't happy about that because they didn't get a clear picture coz they couldn't hold her. So, all they can say to me is "oh don't worry, we don't think there's anything wrong" but they didn't change anything and I'm so worried till now, so we've been seeing on and off with Dr.D and now we've see a chest specialist at [Place] centre and that's our 4th time to see him and him to have tried changing

Comment [L128]: Obvious pain – commonly noticed amongst parents so far

Comment [L129]: Difficulty recognising pain, guesswork

Comment [L130]: Signs suggesting pain

Comment [L131]: Non verbal communication

Comment [L132]: Sign suggesting pain

Comment [L133]: Hiding / minimise pains

Comment [L134]: Impact on carer

Comment [L135]: Pain management strategies

Comment [L136]: Impact on carer

Comment [L137]: Sign

Comment [L138]: Monitoring, observing

Comment [L139]: Impact on carer

Comment [L140]: Dissatisfaction with health care provider

Comment [L141]: Reassurance by professionals

Comment [L142]: Impact on carer

the pillow, like I check S about 2 or 3 times at night times when she sleeps, because it really frightens me because sometimes the coughs come in the middle of the night and the cough is like, coz she's a big girl, you can hear the cough, pup pup. Pup pup. You know.

15. *Yeah so you can hear it in the chest...*

16. Yeah so I was thinking, is this the lungs, you know as a mother, a lot of these things come to your mind, what is this? And you think the doctors are not doing enough for S because I don't think S is the only person that has this disability or whatever, there's some other children or other people like S but I'm talking about my own experience with S. I'm very worried about S's coughing so it's like now the doctor has put us Doctor X, his name, is like when she's eating, so he sends some physio person we saw, her name was, I think M, last month, so she came to us to how S eats and see that if the cough is to do with how the food goes down. And I told her plain that S is a person that wouldn't rush food. Anywhere that she goes I always tell them I said "please she takes time to chew what is in her mouth". She will sit down for maybe near an hour to finish her dinner and I always let her. So she's not a person that would rush food and she likes to finish what she is eating before she drinks. So I always let people know that you know, please let her, it takes time for her to chew, don't rush her, coz if you rush her she gets a bit upset. S is not an embarrassed person but once she gets like that that's when she pushes you out and she's a big girl she can.. so she's now, the time they had introduced her we had been on the pump listing, because now they're thinking it might be asthma or whatever but they are still not sure, so right now we are doing the pumping with the, what do you call it, the puff..

17. *The ventolin.. inhaler?*

18. Yeah inhaler, but it's still very difficult because S doesn't know how to do it properly so we do it so many times a day. And I just say that if a little bit goes down it does go down because I was, if there is anywhere we can go or is anyone going to go to us to teach us, to get time for, you know, we didn't get nobody, it was when they introduced the pump to us they just went to the nurse room and the nurse was standing there but S doesn't understand this! S can't do this! So I was saying "Is there any other way?" Because it was very difficult and S was getting very frustrated when people were telling her to hold it in and she tired and she will push it back and that's you know, that's the time that with these children, if something is wrong they can't tell you. So I always say, I wish there was another way that they can treat these to know where the pain, or whatever, to treat, I mean I know they are not god but...

19. *Yeah but it's a big worry for you.*

20. It is a big worry.

21. *Because it sounds like you've tried lots of things but ... ok I mean, you've talked a bit about how you manage S's period pain, are there things that make it difficult to manage or easier to manage do you think?*

22. Well when she has the pain what I do to make myself, you know, not to get too much stress, like I stop it, when to the centre coz I don't know, I say to myself what I would do they will do it. I know definitely it wouldn't be the same thing because it's not only her they're looking after at the centre but because now S has a one to one carer that I can tell her that this is what I want you to do. If she's not happy to do it or if she's gets to a certain place where's she not pleased, don't wait for the boss, use their money or get a cab and get a receipt and use the money for that so it's a little bit easier now for me.

23. *So you can kind of rely on her?*

24. So yes, I can tell her one to one and say that this is what I want her to do. Before that she used to go to the big centre and there are so many children and maybe 1 of 3 of the children would have the same problem, and they go out and when S is like that she doesn't want to go out, she doesn't want to walk because she tends to bleed a lot for the first 2 days, she's a person that whenever she sees 1 or 2 drops on her thing she wants to take it, she wants a new one to put it there, and when she gets tired she doesn't want to put it there at all. And I mean, even we get fed up when it's there, it's not comfy when it's there but, you know, you have to talk to her to understand that it has to be there, S, then she'll get used to it.

Comment [L143]: Dissatisfied with HCP

Comment [L144]: Impact on carer

Comment [L145]: Non verbal communication

Comment [L146]: Another way wished for

Comment [L147]: Pain management

25. *Do you think it's hard for her to understand why she feels that pain every month?*
26. I think it's very hard for her to **understand** so.. some might say that because of that problem they have taken some like, the doctors have given her some tablets to stop the period completely
27. *Like a contraceptive?*
28. Yeah, that can cut off the period, but with me I say no she's a woman, and she's a young lady and that's a god nature, I'm not going to stop that. I'm not going to stop that, I don't know.
29. *She should be allowed to carry on as a woman.. But you heard off people who have...*
30. Yeah I know some other parents that have done that but because S is not a 'carry weight' person. These tablets go with the big weight on, you have to you know, know that all this weight will always come on 'cos they're gonna carry that on.
31. *So it's like a side effect..*
32. Yes, like I didn't like the idea of the situation. Although it's still hard, but I still you know I try and get through it or it depends some of the months, its gets very very... and she won't even eat then I ask the carer to stay with her. You know that, 'cos she doesn't want to go out so you know, we stay home and it normally comes to like 4 days and the 5th day morning you see that she's fine.
33. *Yeah. What's it like for you as her mum then, seeing her every month going through this pain?*
34. It is very **stress**, it's very very painful. I mean S is god, she is a young lady, woman, she could have done it, thing, like, I wouldn't have seen all this S would go out and buy her own you know, things, the young girls they like tampons, you know that business, they like to wear jeans they don't want to be, you know. It is very hard, and you can get your own little, when you have a pain you know it tends to go. But it does get me really really really down when she's in pain and that gets to me as well. In the beginning I used to cry with her when she was in **pain**. But what can you do?
35. *Yeah, do you think over time it's got easier to see or do you think it's still as painful?*
36. It's still painful, but then there's **nothing** I can do and there's no way that you can... who am I going to dump her on? No.. some people suggest to let them, like that week, to go to respites they choose at times so they.. no. everybody is different so..
37. *Yeah yeah.. ok. So that's about a time when it's kind of quite obvious that S is in pain. So are there times, do you have an example of a time when it's not been so obvious when she's in pain and you haven't been quite sure?*
38. Yeah sometimes when it's not the period problem... she had a flat foot in her left leg and I noticed that sometimes when she's in pain the lower part of the leg would sometimes would **swell** up especially when she does walking loads. You can see that's she's limping a little bit and you **notice** that she's in pain and you see that, as I said, because I always look at her **face** because that's what I'm.. you know, I know that when she's not...
39. *So will you notice similar things, compared to period pain, notice similar things in her face if it's to do with her foot?*
40. With her foot or her body pain then maybe it's, I notice that S will another thing, like she will **change** completely.. she gets like uhh.. well, my sister said that maybe it's in my mind. But she gets a pus on her mouth, like a cold sore on their face and the mouth and I notice that she's not very well
41. *Yeah so you can see she's not right?*
42. Yeah, not right. So I always try, she doesn't like tablets, so I was trying to **hide** it on her food, food that she eats but she found out and she doesn't like me to do it
43. *She's not happy with that...*
44. Yeah she's not happy with that, so it takes time but then I cut it with like... 'cos she sees me taking some tablets out so I always take it with her, let her see that it's not going to harm her, like "look mummy's one". We make a little song, she likes music, and then she'll

Comment [L148]: Perceived understanding difficulties

Comment [L149]: Impact on carer

Comment [L150]: In synch emotionally with daughter

Comment [L151]: Helplessness?

Comment [L152]: Sign of pain

Comment [L153]: Monitoring

Comment [L154]: Sign of pain

Comment [L155]: Notice behaviour change

Comment [L156]: Notice visible sign

Comment [L157]: Strategy!

give me a smile and she'll take it in her mouth and I'll give her her favourite drink to go with it

45. *So if she's in pain with her leg you'll notice she might get cold sores...*

46. Yeah cold sores, because she's been with it for so long time, I keep saying that then I will see, I will check her body and say "S pain here?" And maybe I will check her ankle because in that happening at first. Sometimes I see that, sometimes it's a little bit different, and I said "oh yeah S". Or if it's like a body pain or headache then if you touch the head maybe you'll see a little bit warm or sometimes when you touch her arm then maybe...

Comment [L158]: Strategy - checking

Comment [L159]: Ask about pain

47. *So she pushes you away so you can kind of make an educated guess...*

Comment [L160]: Strategy – look for signs

48. Yes, yes. And maybe I'll try the next day to book an appointment with the GP. She will always use every system as a check up and see like, blood pressure, weight, we were doing like, blood tests, but blood test are not easy to do with S..

Comment [L161]: HCP uses all available resources

49. *Yeah... she doesn't like it...*

50. No, she'll fight with a hook (laughing)

51. *Yeah, lots of people do... and so with that, when you suspect that she might be in pain... are you generally always right if you go to the doctor, is there generally something, so you can pick up what's going on with her...*

52. Yes yes yes. She says it's a good thing I always.. you know, so yes, I always check S out.. I always do..

Comment [L162]: Listens to HCP advice

53. *So you're a bit of a detective...*

54. Yeah, that's what my son calls me (laughing) I always do and I always tell her, the carer, to write down whatever you did with her in our book that put it in so she tells me when she comes that "oh S, I tried to do this but she doesn't want to do it. She didn't eat at lunch maybe she's so...

Comment [L163]: Detective

Comment [L164]: Write down as monitoring record

55. *So do you do a lot of monitoring of her do you think? Of her behaviour and kind of what she's been eating and things like that?*

56. I do, I do

57. *And you think that helps you to tell when she's unwell?*

58. I think that tells me a lot when she's not well... because I do, as I said, I do look on occasion with the carer, that this is the food I want S to eat at lunch time because I do I cook everyday when she comes in. I know what she eats. So this is what she drinks when she goes out and eat when... to let me know what she does

Comment [L165]: Monitoring helpful

59. *So if her behaviour changes, if say she's a little bit more quiet or withdrawn or she's behaving a way that's a bit more, kind of, challenging than usual, what do you generally think is going on?*

60. I just don't know... You just have to guess.. and guess.. sometimes it will take a few days then you will just get it, "ooooh maybe it was this". You don't get it all, it's very very difficult. It's very very very difficult. You don't... It's not easy. It's not easy at all. it's very very difficult

Comment [L166]: Guesswork = slow, difficult

61. *And do you get any support from anywhere else? Are there people around you can ask? The internet? Are there places that you can find out more if you're a little bit stuck?*

62. No. but I have this group where I go, where you saw you. The lady doing the tea she was the one who was doing it before,

Comment [L167]: Info at carers group

63. *Yeah yeah she's retiring isn't she..*

64. She's retiring yes and she's a very very good woman and she helps a lot. And we tend to, like as we saw you, when you go to such meeting, you get to hear other people saying, this is what I do to get this, to find out, about the other lady was speaking when you were there the other day, about the daughter, they can hide pain. S can hide pain. Even when they have pain they don't want you to know, but you have to go in to know.

Comment [L168]: Perception of hiding pain

65. *So you think she can hide it?*

66. Yeah she can hide, because as I said, I mentioned the other day when you were there that she had this boil in her armpit, and she hide it so long and I didn't even know because she went away with the group for two days I think that's when she got that, I didn't find out. And then she was going out in the morning every single day and I was the one bathing her.

Comment [L169]: Unrecognised pain

And I said, because it didn't click with me that I remember that the very first day when she came back from the holiday and I put her in the bath.

67. *So you were talking about having not noticed that she had this boil under her arm..*

68. Yeah, so, that's why I'm saying, you think that you know everything but sometimes things just slip, and I said, it was just about something like this, why didn't I know this? And I was so so very very angry that I couldn't find out but you know, I was sitting down and I remembered that, "oh I remember that when I was holding her arm she".. and she does that a lot..

69. *She pulled away..*

70. Yeah she pulled away, and I said "ooh alright", and I just rubbed her down, but I should have found out why she was pushing in that side.. so it's not easy. It's very very very hard

71. *So what do you think that was about then that she didn't want you to lift her arms?*

72. Coz she didn't want me to see.

73. *And why do you think that was?*

74. That's what I was saying that sometimes these children they hide things. They hide pain. And if it was me having that pain I would have cried or showed it, or you know, let everybody know that I'm in pain or go to the GP, call and book an appointment because I am in pain. But look, she hide it, and god knows how long that thing was there and I myself didn't even find out until that day that I saw tears coming from her eyes and I noticed that she couldn't even lift her hand..

75. *And has it changed how you look out for things?*

76. Oh yes oh yes. Because it's been about 3 years now, it's changed me a lot

77. *In what way?*

78. It's changed me a lot.. I even told the carer that you are responsible for her when you take her out so if she does something like the other day at the centre gym and I think there was something that she didn't want to do and the carer said that she was trying to help her to do, I think her bra or something like that and I think she didn't want to go, she didn't want to do that but she said that S just push her, and she said "I stopped it" and I said, "why did you stop it? Maybe it was something that she was trying to tell her". So I said to her you have, even if you just hold the bra, let her know that you are going to do this, tell her first. Although she can't speak she can get some idea, a little idea, if you break the sentence down like... "S - gym. S - we going gym". And she will, you know, she will do something to let you know that yeah it's that one that I like, or that one that I don't like. So every since that one I always try to be extra do things extra with her. Ask them things that she likes. So sometimes that she likes to show to her so that she jump my mind to another side to let me know I don't always give up quick with her.

79. *Yeah, so you have to kind of, persevere?*

80. Yeah.

81. *And so we talked about if she was behaving in a different way that it's kind of hard to know what might be going. I mean, are there particular things you look out for, particular signs that will show you that she's likely to be in pain?*

82. Yeah.. as I said it's just guess guess guess guess.. and you can't guess one thing and just drop you, it have to guess in the end, what I do is I have to, when she is in the room and I am sitting down here, I don't sit down here for long I always sneak upstairs and check and see what position she is sitting and see how she normally sits, and I put the telly on with her and you think that she's watching the telly, she's not. That's another way that I notice that she's in pain. She will sit on her bed and fold her arms like that. And just not watching the telly. And she folds her like this. And if I sit down here like nothing that S is watching telly, 'cos the telly is on, I won't find out. So I always check..

83. *So you check on her a lot?*

84. I check on her a lot

85. *And that's how you know.. Does she have any particular health conditions or anything? That you're looking out for? Or is it just general things?*

Comment [L170]: Perception of confidence in ability to recognise pain

Comment [L171]: Pain gets missed

Comment [L172]: Emotional impact

Comment [L173]: Difficult to know

Comment [L174]: Hiding pain

Comment [L175]: Comparing her pain expression to her daughters

Comment [L176]: Sign of pain

Comment [L177]: Guesswork

Comment [L178]: Monitoring for pain

Comment [L179]: Signs

Comment [L180]: Need to check

86. Yeah just general things. And now that they have jumped into this asthma things I'm thinking maybe its asthma that is the coughing and now its not a big worry. That I'm the worrier, I don't think with me, because we don't have the asthma in our family. So my big worry is that maybe it has something to do with her lungs, that is my biggest worry now.

Comment [L181]: Emotional impact

87. Yeah, and in terms of S communicating that she's in pain to you... do you think its always about you guessing first or has she ever sort of indicated by pointing or something that something's wrong...

88. No its always about me knowing and guessing

Comment [L182]: Guesswork

89. Yeah, ok. And if it's likely that she will be in pain, say she's been to the dentist or something how do you monitor her for signs that she might be in pain after that?

90. Ummm... know that you're talking about dentist we were just planning to go and see the dentist, coz we haven't seen them for a little while.. and let me tell you, I noticed that at the weekend when she was eating she was juggling food from here to here and I noticed that this morning when she was brushing her teeth and I said "ahhhh lets have a look".

Comment [L183]: Noticing/monitoring for signs

Maybe you know, a little hole or whatever in her left side so I'm thinking about booking a dentist because it's very very difficult with the dentist as well for S to assist the dentist is very very difficult, even now.. I don't know which we're going to go now. The latest one where we went about a year ago was [Place] hospital and there they put her to sleep..

Comment [L184]: Difficulties at dentist

91. Would she be very anxious if she was awake?

92. Yeah. The doctor told me that it's not good, but I didn't like it, it's very awful, it's very, you know, with me, for the sleeping part coz S was struggling with them and you know, I didn't like that so I didn't want her to go to that anymore. So.. I am going to speak to our doctor to see if there is another specialist that she can see

Comment [L185]: Interaction with HCP

93. Yeah it's very difficult isn't it going to the dentist because a lot of people don't like it do they..

94. Yeah I don't like it myself so imagine S. even thinking about it now...

95. But you've noticed a little hole and you noticed that she was juggling food..

96. Yeah, she doesn't do that

97. Does she indicate that there might be pain there?

98. Well this morning I was just touching it and she brushed me off, just pushed my hand. And then I said to the carer, I'm worried about S's teeth, I think there's something wrong I think she needs to be checked because she won't let me see and I was trying to see more, trying to find out if she will open up more for me to see more to see properly. She didn't. She didn't. And then I noticed that there was something wrong, and it jumped back in memory to the weekend when she was eating and I was sitting next to her and she was struggling to eat..

Comment [L186]: Gesture as a sign

Comment [L187]: Talk to others

Comment [L188]: Emotional impact

Comment [L189]: Noticing

Comment [L190]: Sign

99. Yeah, so you've noticed something.. I wonder what you think about S's pain threshold, whether you think that her kind of, threshold for pain is higher than other peoples or lower or about the same?

100. Well I can't tell about the other people's pain I can only tell about my own daughters pain.

101. Do you think her threshold is higher for pain?

102. Yeah, uh huh.

Comment [L191]: Higher pain threshold is perceived

103. What's makes you say that?

104. Well because, S is a person that likes going, so when I see any difference then I know that she can hide pain. So maybe the time I find out that she's in pain, then she must be really in pain. Really in pain. Because S can hide pain, and really hoard pain. So.. I don't know, maybe, I don't find it straight away..

Comment [L192]: Hiding pains

Comment [L193]: Tolerance for pain?

105. So that makes you think that...

106. Yeah.

107. And what about just generally other adults with learning disabilities? Do you think that their threshold for pain is the same as other people or different?

108. Well with special needs children I think their pain because they can't say "ooh I've got a headache ooh lord", you can see a headache coming and maybe you take a pain killer, but by the time you find out that the headache is "ooh maybe they've got a headache, maybe

Comment [L194]: Cannot verbally communicate pain

that you've gone so far through the night" that you and me can be like, "ooh I'll just take a painkiller before I go out" so I think their pain is more painful than ours because we feel the pain so quick and we take something to do something about it but they have to wait for you, they have to wait for us to you know, to do something for them, so I think they go through a lot. It's very painful.

Comment [L195]: Helplessness? Waiting for people to do something

109. What about S's tolerance for pain, like how much she can endure.. do you think that that's high?

Comment [L196]: More pain experienced?

110. It is high because that's what I was saying, that she hides pain

Comment [L197]: High tolerance for pain is perceived

111. Yeah. And what about other adults with learning disabilities? Do you think that they have a high tolerance for pain?

112. Well I hear about some of my parents the same way I'm talking to you, even if you did listen to the other time when you were there, I hear about you know, saying the same similar things as what I'm saying.

Comment [L198]: Other parents share her opinion

113. So it's from hearing from other people?

114. Yes I've been hearing from other people, other families.

115. Ok, and in terms of S getting her pain recognised and treated by other people, do you think that that's difficult or easy for her?

116. Like easy for her to be treated?

117. Yeah well I suppose we talked a lot about how you recognise pain but what about getting it treated?

118. It's not easy. And it's always hard. I don't think she gets the real treatment like any other ordinary person will keep saying "listen, I'm taking this one and it doesn't go with me" and S is always like try and let her finish this and we'll see.

Comment [L199]: Treatment is hard

119. So the doctors will say carry on with this..

Comment [L200]: Comparisons with typical people

120. Yeas, and let's try this and let's try this, so it's difficult. While any other person would say, "look I tried this and I don't like this because the pain goes to this part, the pain is there, I notice this way".

Comment [L201]: Difficulties with HCP treatment

121. So do you think the difficulty for her is around not being able communicate verbally with the doctors?

122. Yes, and the difficulties that the doctors don't understand, I think they don't understand and I think they don't do proper checkups, they don't have any specialists, or whatever, or any other ways to go.. you understand me, through these children.

Comment [L202]: HCP dissatisfaction

123. Well, in terms of when you go to a consultation with S, how does it generally go, will the doctor ask you for lots of information?

124. Yeah. She asks everything of me coz S will just sit down.

Comment [L203]: Communication with HCP

125. Yeah, and do you feel satisfied when you've left?

126. Well, not satisfied but I have to take it like that. I have to, what can I do? I can't do anything.

Comment [L204]: Dissatisfied with treatment

127. What do you think the obstacles are for getting her pain treated?

128. Well... I mean, as I said the pain is not completely treated because she always hear that there's nothing that we can do to change S, she will be S for the rest of her life. So you don't, you know, I use to, I let it get me down down down and I get myself sick and I know now that if I get sick the only person my daughter will end up with at home is herself.. so I have my faith with god, and prayer, and do things around that. God gives me strength and light to look after her.

Comment [L205]: Pain still present

129. So that's something that helps?

Comment [L206]: Emotional impact

130. Yes and my son supports me a lot

Comment [L207]: Faith as support

131. Are there other things that help to get her pain treated?

Comment [L208]: Family support

132. No I have to guess myself, get painkillers or do something with her and now I notice that she likes massage, so I'm trying to use some of her money to take her to private massage every month.

Comment [L209]: Guesswork

133. So you know, you'll try painkillers, you try massage, is there anything else you try for pain relief?

134. No, apart from the painkiller. We haven't started massages yet, we're starting at the end of this month.

Comment [L210]: Pain treatment

Comment [L211]: Alternative treatment

135. *And you talked about a hot water bottle as well?*
136. Yes during period time, and I've started to use the foot bath thing, I just bought one last week for her foot, so see if it will massage her foot. And umm, next week we are going to start a special **swimming** lesson, as they said its good for her, for her lungs and all that.
137. *So just like gentle exercise?*
138. Yeah.
139. *So in terms of painkillers what ones will you generally offer her?*
140. I **always** give her Anadin.. because that's what I take and I notice that wow, I know its good for me so I always give her anadin.
141. *So if you give it to her what signs will you be looking for to see if it's helped*
142. Coz when I take it, it takes about an hour for the pain to go so, and when I take it I notice you have a little bit of sweats, especially when you've had a headache or pain, you have a little bit of sweat on your face, like you feel like you sweat a little bit, and you feel that your temperature is going, and I found out that that's good for her as well.
143. *So do you **look** for that in her?*
144. Yeah I always look out for that with her when I give her, I normally give her like at night time when she's going to bed and in general I **notice** that its good for whatever that she does go deep sleep, like I hear her snoring a little bit, she does go deep sleep. For a little while yeah.
145. *So does that tell you that the painkillers have worked?*
146. Yeah, and in my heart I will say to myself I think she's **settled** down now
147. *Yeah, and how do you feel about S having painkillers, what's your view on painkillers?*
148. I don't give her painkillers all the time, because I know they have side effects if you take them too much, so I don't give her **painkillers** all the time, I always try to do some other things with her like, **massage** especially when the foot is paining, massage the legs, or give her oil massage on her back. Recently I bought this headache oil that this man were selling at one of the meeting they say you just have to rub it on their chest for it.
149. *So you try kind of alternative things? So when does it get to the point where you think that you will give her a painkiller?*
150. When I **notice** that she's still, the pain is not still not, past maybe half an hour and she's not still sitting down, then I add the painkiller on it.
151. *Ok, yeah. Alright, so we've nearly finished now. I just have a question just about you and your pains. I just wonder if you could remember the last time that you were in pain?*
152. Ooh, because of I'm a sickle cell sufferer. My body is always in pains, sometimes the pain will continue and my **pain** will feel so tired. And I have to lie down for more time. I have to spend more time lying down. And sometimes you're ok but it comes in the morning and the body is aching and you know, everything is aching. But I've been on it for so long my body's used to it now..
153. *So I mean, what's your strategy when you're in pain?*
154. Take my tablets and lie down.
155. *So do you have painkillers that you can take?*
156. Umm I have, I'm not into painkillers that I take right now, that I take every day. Unless im in pain pain very pain. Because I have my own medicine that I take every day that will boost my energy up. So that's something that I take every day. But when, because when sometimes when its time, there's nothing that you no, the tablets will do, then it comes that you need to lie down and it tends to come down to oh, you know.. you have to lie down..
157. *So you have to rest..*
158. When you feel you have to lie down, it would be very difficult if you don't do that and you continue like you're still strong so you can come out through the door. And last year I was like that I thought I was going to die, I don't want to go through that again.
159. *Yeah, gosh. So you're taking better care of yourself?*
160. Yeah, and I've lost an awful weight as well because I can't even eat food. So.. for the past, god, from march I haven't been sick.

Comment [L212]: Alternative treatment

Comment [L213]: Same painkillers as for self

Comment [L214]: Noticing

Comment [L215]: Noticing

Comment [L216]: Comforting self?

Comment [L217]: Painkillers

Comment [L218]: Alternative treatment

Comment [L219]: Monitoring

Comment [L220]: Own experience of pain

161. *I just wonder because you know, with your sickle cell you are in lots of pain, I just wonder do you think you're more conscious that you're children might be in pain and that S might be in pain because you're used to feeling it?*

162. With Z, my son, from age about 2, when anything happened he said "ooh mum I hurt it, mum my head". But you know, so Z will know what to do. My big worry is S, that is my big worry. That is the reason why I've put more effort in S, I check her a lot to find out because I know that she's good in pain, she can hide pain. So I take that to know more about her or check her more often to find out how she's doing

163. *Yeah. And this idea that she hides pain.. I just wonder how this makes you feel?*

164. It really hurts. It really really hurts, you know when you find out that she's been feeling this pain.. how long has she been through this? Has she been through this for a day and I didn't know? And it does really bring you down, gets me really down. At least S is happy, I can see from her face, she brights up, she likes, she will smile at you, she gives you a smile,

165. *She lets you know?*

166. Yeah she will let me know like this morning coz the carer she comes in to do some work before they go and by about 9 o'clock they are all out of the door. But Wednesday they stayed in until about half past 9 before they left the house, so when she was going you could see it was a good mood and she wanted to go out, and she took the carers hand and she said good girl and her face was bright up that she was happy with what she was doing and I always tell her to give her a reward when she does something good.

167. *Ok well that's all my questions for you. How did you find it talking about this?*

168. Uhh.. I was very interested when you came to mention this, its something that I was so so, I was telling the other girl that I was sitting next to, and I said, I always talk about this but I WISH someone would come up some day to ask, to ask, I mean, to come out and say are you feeling this thing? And it's something that I've had at the back of my mind for so long. Any time when S is in pain or when she's not feeling well, S is ill, it always comes to my mind. Even not then, it's always in my mind, coz these doctors don't understand, I don't think they do. So I was so glad that I even came to that to meet you and it was such comfort that it was so good that you are a young lady that comes and wants to do, coz I know, coz there would be so many people that would like you to come to their home, and you will hear the same thing that you hear here, that we are going through. And I was so glad to hear that you came round to ask these questions because it's something that I've been (unclear) all the carers say that when you see them, it's the same thing that every parent is going through

Comment [L221]: Emotional impact

Comment [L222]: Checking, monitoring to learn more

Comment [L223]: Hiding pain

Comment [L224]: Emotional impact

Comment [L225]: Emotional impact

Comment [L226]: Sign of being okay

Comment [L227]: Notice her mood

Comment [L228]: HCP do not understand