1 The psychological and social consequences of single-sided deafness in

2 adulthood

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18 **Conflicts of Interest and Source of Funding:**

- 19 This work was supported by infrastructure funding from the National Institute for Health Research
- 20 (NIHR). The views expressed are those of the author(s) and not necessarily those of the NHS, the
- 21 NIHR or the Department of Health.
- 22
- 23 This is an Accepted Manuscript of an article published by Taylor & Francis in the
- 24 International Journal of Audiology and available online at:
- 25 http://www.tandfonline.com/toc/iija20/

26 Abstract

Objectives: This study examined the subjective psychological and social effects of highly
asymmetric hearing loss (single-sided deafness) in adults.

Design: Three group interviews were conducted using the critical incidence technique and
 analysed using an inductive thematic analysis.

Study sample: Eight adults with a clinical diagnosis of a moderately-severe hearing loss or
greater in one ear and normal or near-normal hearing in the other ear.

33 **Results:** A range of functional hearing difficulties associated with single-sided deafness

34 including impaired speech in background noise and reduced spatial awareness were reported

35 to affect social and psychological well-being. Social consequences of single-sided deafness

36 resulted from activity limitations and participation restrictions including withdrawal from and

37 within situations. Participants reported psychological effects including worrying about losing

38 the hearing in their other ear, embarrassment related to the social stigma attached to hearing

39 loss, and reduced confidence and belief in their abilities to participate.

40 **Conclusions:** Single-sided deafness can be associated with many negative consequences.

41 Counselling may help overcome the psychological consequences of hearing loss regardless of

42 whether technological support such as a hearing aid is prescribed. The audiological

43 management of these individuals should support the development of listening strategies and

44 set appropriate expectations for participation in everyday listening situations.

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Key Words: unilateral hearing loss; unilateral deafness; single-sided deafness; SSD; hearing
function; listening difficulties; psychosocial impact; critical incidence technique

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50 Introduction

51 Single-sided deafness (SSD) refers to a highly asymmetric unilateral hearing loss. An 52 international consensus statement has defined SSD as a 'severe-to-profound' hearing loss in 53 one ear (pure-tone average threshold $\geq 60 \text{ dB HL}$) and normal or near-normal hearing in the 54 other ear (pure-tone average threshold <30 dB HL) (Vincent et al, 2015). The prevalence of 55 SSD has been estimated to be about 1% of the general population (Davis, 1995). SSD is 56 often associated with sudden onset sensorineural hearing loss, the incidence of which is 57 approximately 20 cases per 100,000 inhabitants per year in developed countries (Byl, 1984). 58 The incidence of SSD in the United Kingdom has been estimated to be between 7000-9000 59 new cases per year based on available data (Baguley et al, 2006).

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61 While access to one well-functioning ear allows individuals with SSD to appear largely 62 unimpaired in the confines of a quiet room, their lack of access to two functioning ears can 63 lead to a clinically-significant degree of audiological disability in everyday life (Choissoine-Kerdel et al, 2000; Dwyer et al, 2014; Iwasaki et al, 2013; Newman et al, 1997). The loss 64 65 of hearing in one ear severely disrupts the spatial aspects of hearing (Douglas et al, 66 2007) and impairs the ability to understand speech in the presence of background noise 67 (Hawley et al, 2004; Welsh et al, 2004). It can be difficult to restore access to sound in 68 the impaired ear through amplification using conventional devices such as a high-69 powered acoustic hearing aid due to the sensorineural nature and extent of the hearing 70 loss in these individuals (Valente et al, 2015). The current standard of care for SSD in 71 the United Kingdom is the contralateral routing of signals (CROS) aid (Kitterick et al, 72 2014), a device which reroutes sound from the side of the impaired ear to the hearing ear for the benefit of speech understanding in noise (Arndt et al, 2011; Arndt et al, 2017; 73

74 Busk et al, 2014; Hol et al, 2010; Lin et al, 2006; Niparko et al, 2003; Ryu et al, 2015). 75 A similar effect can be achieved using a bone-conduction hearing device (BCHD) 76 (Desmet et al, 2012; Finbow et al, 2015; Kompis et al, 2017; Newman et al, 2010; Saliba 77 et al, 2011; Schrøder et al, 2010; Wesarg et al, 2013) with the potential for even better 78 benefits to speech perception and sound quality compared to CROS devices (Kitterick et 79 al. 2016). Cochlear implantation has the additional benefits of restoring access to 80 binaural cues that underpin speech perception in noise and sound localisation (Arndt et al, 2011; Arndt et al, 2017; Finke et al, 2017b; Hassepass et al, 2016; Jacob et al, 2011; 81 Mertens et al, 2015; Távora-Vieira, 2015; Vermiere and Van de Heyning, 2009), which 82 83 longitudinal studies have shown to be sustained over the long term (>10 years) (Arndt et al, 84 2017).

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The functional consequences of SSD have been associated with a range of psychological and 86 87 social consequences. For example, individuals with SSD can report increased stress levels 88 related to their need to seek out optimal positions within social settings in order to 89 maximise their ability to hear and participate (Hansson, 1993, cited in Wie et al, 2010). As a result, individuals with SSD can report feeling excluded from social situations (Wie 90 91 et al, 2010) and perceive their social life to be restricted by their hearing loss 92 (Subramanium et al, 2005), leading to high levels of hearing handicap (Dwyer et al, 93 2014; Iwasaki et al, 2013). Numerous studies have demonstrated that rerouting sounds 94 between the ears using CROS or BCHD significantly reduces the perceived difficulties 95 with listening in everyday life thereby improving hearing-specific quality of life (Busk et 96 al, 2014; Finbow et al, 2015; Hol et al, 2010; Kompis et al, 2017; Lin et al, 2006; 97 Niparko et al, 2003; Ryu et al, 2015; Schrøder et al, 2010; Wazen et al, 2003). However, 98 some studies have suggested that there can be increased aversion to loud sounds with the

99 use of CROS devices (Lin et al, 2006). Cochlear implantation has also been associated 100 with benefits to hearing-specific quality of life, with the additional benefit of reduced 101 difficulty with identifying the location of sound sources, navigating everyday 102 environments and tinnitus relief (Arndt et al, 2011; Arndt et al, 2017; Finke et al, 2017a; 103 Härkönen et al, 2015; Mertens et al, 2015; Ramos et al, 2015; Távora-Vieira et al, 2015; 104 Van de Heyning et al, 2008). Arndt et al (2011) also demonstrated that cochlear 105 implantation can have broader benefits on health related quality of life as measured by the Health Utilities Index Mark 3. However, cost-benefit analyses are still needed to 106 107 assess whether the size of these broader benefits are sufficient to justify the costs of 108 cochlear implantation (Kitterick et al., 2015). These analyses will need to be conducted 109 from a specific perspective as costs will vary across countries, healthcare systems, and 110 funding models (private versus publicly funded).

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112 Previous studies have primarily used self-report questionnaire instruments to both 113 characterise the burden that SSD places on the individuals and the benefits that devices can 114 have on quality of life. Examples include the Monaural Auditory Capacity Assessment Scale 115 (MACAS) (McLeod et al, 2008), the Speech Spatial and Qualities of Hearing Scale (SSQ) 116 (Gatehouse & Noble, 2004), and the Auditory Profile of Hearing Aid Benefit (APHAB) (Cox 117 and Alexander, 1995). While these instruments are efficient to administer and straightforward 118 to analyse, it is possible that the use of closed questions places limits on the breadth and depth of the information gathered (McColl et al, 2001; O'Cathain & Thomas, 2004). 119 120 Qualitative methodologies can be particularly powerful when seeking to capture the full 121 range of difficulties and consequences associated with a health condition (Flanagan, 1954). 122 Very few studies have applied qualitative methods to explore the consequences of SSD. Giolas & Wark (1967) use a method called the Critical Incident Technique (CIT) to generate 123

discussions around the situations that patients themselves recalled as being problematic as
a result of their hearing loss. The results helped enumerate the many ways in which SSD
imposes functional limitations on the individual, largely through impairments to speech
understanding in noise and the ability to localise sounds. However, to date the psychological
and social consequences that SSD imposes have not been explored or characterised in the
same level of detail that qualitative methodologies can provide.

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131 The aim of the present study was to address this gap in the literature by conducting an indepth qualitative investigation of the psychological and social consequences of SSD on 132 133 everyday life. As there may be distinct differences between short and longer-term 134 consequences of unilateral hearing loss, particularly where its onset is sudden (Sano, 2013), 135 the current study focussed on the longer-term consequences in those who had lived with SSD 136 for at least a year. By using the CIT method, the study was able to explore the full extent of 137 these consequences and provide insight into both the situations in which they arise and the 138 impacts they have on the individual. The study also gathered information on the strategies 139 that are developed to cope with these consequences and to enable continued participation in everyday life. The results increase our understanding of the overall health and well-being of 140 141 adults with SSD.

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143 Materials and Methods

144 Sampling and recruitment

Participants had a clinical diagnosis of a sensorineural highly asymmetric unilateral hearing loss (single-sided deafness) for a period of at least 12 months, defined as a pure-tone average of \geq 60 dB HL with at least two thresholds \geq 65 dB HL at 1, 2, or 4 kHz in one ear and an 148average threshold of \leq 30 dB HL in their other ear. Participants had to confirm by self-report149that their hearing loss had not changed in severity within the last 12 months.

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151 Participants were recruited through the NIHR Nottingham Hearing Biomedical Research Unit 152 participant database via email or postal invitation specifically for the purpose of this study. 153 Advertisements were also placed in the Audiology services and Ear, Nose and Throat clinics 154 in local hospitals, the mailing lists of hearing-related charities, and on social media websites. No restrictions were placed on a participants' age, gender or employment status. Participants 155 156 had not already taken part in any related research studies. Participants were screened using an 157 online questionnaire to confirm their eligibility for the study. Those who passed the screening 158 phase were asked to provide a copy of a recent audiogram (taken within the past two years) 159 or invited to take part in a short in-person audiometry assessment to confirm their eligibility. 160 The assessment consisted of otoscopy followed by threshold measurements for each ear using 161 air-conduction audiometry, both conducted in accordance with the British Society of 162 Audiology recommended procedures (BSA 2010, 2012). 163

164 **Participants**

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Eight adults with single-sided deafness living in the UK participated in the study (Table 1).
All participants were native speakers of English. Participants' aetiologies were mixed and
included vestibular schwannoma, meningitis, and idiopathic hearing loss. The mean age was
57 years (range=37-71) and the average duration of hearing loss was 13 years (range=13
months-28 years). The mean threshold in the better ear was 13 dB HL (range=4-30 dB HL)
and 82 dB HL in the other ear (range=61-119 dB HL). A majority of participants (7 out of 8)
reported experiencing tinnitus with varying levels of severity.

173 **Procedure**

174 Three group interviews were conducted using the Critical Incident Technique (CIT). The CIT 175 was employed to create a semi-structured discussion (Flanagan, 1954) whereby participants 176 themselves generate all topics for discussion without prior discussion with others or the 177 researchers facilitating the interview. The rationale for the use of this approach was to ensure, 178 as far as practically possible, that the choice of topics for discussion was not unduly 179 influenced by the prior expectations of the facilitators or only a small vocal minority, but 180 rather reflected the issues that were seen as important and relevant to individual participants 181 (Glaser & Strauss, 1967). Table 2 describes the specific sequence of activities that were 182 undertaken in all three interviews. 183 184 Participants were allocated to the interviews according to the order in which they were 185 recruited. Two participants took part in each of the first two interviews, the aim of which was 186 to gather in-depth information on the experiences of adults with single-sided deafness. A 187 third interview was conducted with four participants to: (a) provide further insight into where 188 those experiences converged or diverged between individuals, who differed in their age, 189 gender and aetiologies; and (b) assess whether data saturation had been reached (Fusch & 190 Ness, 2015). The study protocol specified that interim analyses would be conducted after the 191 second and subsequent interviews, and that additional interviews would only be conducted if

192 new topics were still likely to be identified.

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All participants provided written informed consent prior to participation and audio recordings of all discussions were made for written transcription. Two facilitators were present at each interview. A primary facilitator (moderator) was responsible for maintaining the discussion between participants and ensuring all participants contributed to each discussion. A cofacilitator sought clarification where the audio recording may not have been clear and
documented interactions, contextual cues and nonverbal behaviors amongst participants. The
discussion was allowed to continue as long as the participants were willing or until all the
topics had been exhausted, whichever came first. The research was approved by Central
Bristol NHS Research Ethics Committee (REC number: 14/SW/1065) and sponsored by
Nottingham University Hospitals NHS Trust.

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205 Data Analysis

206 Audio recordings of the interviews and the focus group were transcribed verbatim. A 207 thematic analysis was conducted using NVivo 10 (QSR International, Melbourne, Australia). 208 Themes were identified inductively after assigning codes to the transcripts (Braun & Clarke, 209 2006). Each researcher first read the entire dataset and assigned each individual piece of 210 information one or more thematic codes. The codes were chosen to factually describe the 211 nature of the information being discussed in as much detail as possible and were initially 212 generated by each researcher independently based on their interpretation of the transcripts. 213 After an initial review of the transcripts, the choice of codes used by each researcher was 214 discussed and any disagreements resolved by consensus. The transcripts were then recoded 215 by both researchers using the revised code set. Codes that referred to similar or associated 216 information were grouped into principal themes and sub-themes by the two researchers. 217 Disagreements were resolved by consensus.

218

219 **Results**

A total of 102 topics were submitted by participants across the three interviews that identified
77 situations in which participants experienced difficulty because of their hearing loss and 25

222 situations in which participants either did not experience difficulty or experienced positive 223 consequences (see Table, Supplemental Digital Material 1). An interim analysis of the topics 224 of discussion between interview one and two identified a high degree of consistency with 225 similar topics emerging in both interviews (Table 3). Although the larger sample size of the 226 third interview may have limited the depth of the discussion relative to the two earlier 227 interviews, the topics raised by this larger group were consistent with the first two interviews. 228 A further interim analysis after the third interview showed that no new topics emerged 229 consistently, suggesting that data saturation had been reached (Fusch & Ness, 2015). 230 Following the study protocol, no further interviews were conducted. 231 232 The following sections describe four distinct but related overarching themes in the data 233 related to single-sided deafness: (1) the functional consequences; (2) the psychological 234 consequences; (3) the social consequences; and (4) the positive consequences. The analysis 235 also identified coping strategies that individuals with single-sided deafness develop and 236 employ to maintain social function. The main subthemes are indicated through the use of

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239 Functional Consequences

italic font in the following sections.

Difficulties with *recognising and understanding speech* were reported by all participants. Quiet situations presented the least difficulties as long as only one person is talking at any time and the talker is in view. In both quiet and noisy situations, participants recognised that it was important for the sound of interest to be on the side of their better ear to maximise speech understanding. Noisy situations presented greater difficulties for the participants, particularly where background noise includes speech or is dynamic in nature. P3 said, "*If everyone's talking at once, it's very difficult to extract one person's conversation. It's just a* *noise*". An associated increase in *listening effort* lead to high levels of fatigue, particularly in
situations where participants were unable to move to a more favourable listening position.
Participants also described how turning their head to ensure that the sound source is on their
non-impaired side could be tiring and uncomfortable. Participants reported that their speech
perception abilities are also hindered by the acoustics of a setting. Wide-open spaces
furnished with hard surfaces that reflect sound and produce echoes (examples included train
stations and airports) were particularly problematic.

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255 Without the benefits of binaural hearing, participants reported difficulty with sound 256 *localisation* and the ability to selectively attend to one sound, which to some were deemed 257 the most inconvenient implications of their hearing loss. The inability to localise sounds was 258 reported to cause difficulties when identifying the direction of unexpected sounds, with 259 participants reporting that they often presumed (incorrectly) that all sound sources are located 260 on the side of their non-impaired ear. P1 talked about her first experience of trying to cross a 261 road after losing her hearing due to meningitis: "I didn't know where the traffic was, it just 262 seemed to be all around and that was quite scary". A lack of access to binaural cues also 263 meant that participants were unable to benefit from 'surround sound' in the cinema, or had 264 difficulties when listening to music or audiobooks that exploit stereo effects, rendering some sounds inaudible when listening over headphones. Participants also described a heightened 265 awareness of sounds which was most apparent when they first lost their hearing. P6 said 266 "When I first walked out into the street and buses were going past it was scary...you're so 267 268 super aware of every single noise".

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270 **Psychological consequences**

271 Participants reported that their hearing loss had many effects on both their mental and 272 emotional wellbeing. The *initial reaction* to their hearing loss differed depending upon 273 whether the loss of hearing was sudden or whether it had a determined cause. Participants 274 who had experienced a sudden loss reported feelings of 'shock' and 'fear'. P6 described the 275 experience as "devastating" and "life-changing", especially upon realising his hearing loss 276 was permanent. The psychological impact for those whom the cause of their hearing loss had 277 been determined appeared to be less severe. P5, who lost his hearing after surgery to remove a vestibular schwannoma, said: "It kind of feels like although the single-sided hearing has 278 279 changed my life, so much else happened...I knew I was going to lose my hearing so I'd 280 almost prepared myself for it amongst other things". Some participants found it hard to 281 accept their hearing loss and linked it to feelings of depression and anxiety. P7 said "I 282 remember at one stage, a few weeks after it all happened, just sitting in absolute despair 283 saying I just cannot live for the rest of my life like this". Those who had experienced a sudden 284 hearing loss experienced heightened anxiety and worry about losing the hearing in their 285 other ear, whilst all participants were concerned about age-related decline in their remaining 286 'good' ear.

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288 Participants felt that there was a 'social stigma' or negative perception about their hearing 289 loss from others who often had a lack of understanding and empathy for their communication 290 difficulties. They reported often being wrongly perceived as being rude or antisocial if they 291 failed to respond to someone calling their name or saying 'excuse me'. P1 described the 292 reactions of a stranger when she did not hear them approaching on a bicycle: "I was walking 293 on a path at a nature reserve recently and a cyclist came up on my deaf side and rang his 294 bell. I didn't hear him. Then he overtook and said "are you deaf or something?". Many 295 participants explained how it took time to accept their hearing loss and admit it to others. P4

said, "It did take me a long time to say [I'm deaf] to people. I felt embarrassed. I didn't want
to admit it or something. But now I just say 'look I'm deaf in that ear'".

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299 Participants also reported feelings of *self-stigma* (negative perception of oneself due to 300 hearing loss) and low self-efficacy (belief in ones' ability to participate). Participants reported 301 often feeling 'stupid' or 'embarrassed' due to their communication difficulties, particularly 302 when they had misheard what someone had said or had wrongly identified who was talking in 303 a group of people. Some felt like a hindrance as they had to rely on other people to be 304 involved in a conversation, or felt 'guilty' if they had missed what someone had said to them. 305 Although participants recognised that their hearing loss had reduced their ability to cope with 306 many everyday situations, they did not appear to consider themselves to be in poor health 307 because of their hearing loss. 'Health' for these individuals was more commonly associated 308 with pain and chronic illness.

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310 Social consequences

311 Participants reported problems with social interactions. Interactions with strangers were considered more difficult than interactions with familiar people (i.e. family and friends). 312 313 Strangers showed a lack of awareness and understanding about effective strategies for 314 communicating with someone who has a hearing loss, often shouting rather than 315 repositioning themselves on the side of their 'good' ear. Familiar voices were reported as less 316 difficult to comprehend than unfamiliar voices and those with poor enunciation. Family and 317 friends were seen as more understanding and empathetic and were relied upon to provide 318 support in challenging listening situations. However, even the closest relatives and friends 319 could be resistant to adjusting their behaviours and could show frustration when asked to 320 repeat themselves or talk more slowly. Participants reported a reduction in the amount of time they spent communicating with their spouse due to their hearing loss. They also reported a lack of conversational intimacy as they did not always feel able to engage in conversations at quiet levels without risk of embarrassment. Participants reported feeling marginalised at social events, especially those involving younger family members who are often unaware of the difficulties that hearing loss creates.

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327 Some participants reported that their hearing loss had effects on social interactions in the 328 *workplace*. Colleagues would often not be mindful of their hearing difficulties and would talk 329 quietly or position themselves on the side of their impaired ear. Participants also worried that 330 they would be perceived as less capable of conducting their job. This concern was 331 particularly acute among those who worked in a noisy office environment where successful 332 communication with others was a key element of their role. P4 felt that the difficulties she 333 had experienced due to her hearing loss eventually contributed to her leaving her profession 334 as a journalist.

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336 Participants recognised that their willingness to interact with others and participate in social 337 situations had changed since their hearing loss leading them to withdraw from situations or 338 withdraw within situations. Some participants no longer enjoyed being in places with lots of 339 background noise as it left them feeling frustrated and isolated. As a result, these individuals 340 preferred to avoid or withdraw from participating in such situations which could lead to 341 reduced self-esteem. P3 said "If I can get out of going to an event I do, because I wouldn't be 342 able to enjoy the conversation... I wouldn't be able to hear properly". Participants also 343 reported withdrawing from meetings at work where they anticipated that it would be difficult 344 to participate. Other participants described how they felt that it was important to engage back 345 into their everyday life, especially by having a physical presence at social events they

enjoyed attending. However, in more challenging situations, such as those with background
noise or where they were unable to choose a favourable positioning in a room, they would
often withdraw within themselves as they were not able to wholly engage and participate. In
turn, this could lead individuals to feel detached from the social group.

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351 Positive effects

352 The limited positive effects identified by participants primarily encompassed a positive effect 353 on the *quality of their sleep* as lying with their good ear on the pillow blocked out unwanted 354 background noise. Conversely, some participants worried about failing to hear important 355 sounds such as a smoke alarm, telephone ringing or a child crying whilst they were sleeping. 356 All participants reported that they had been able to find constructive ways in which to adapt 357 to their hearing loss and recognised the importance of positive support from family and 358 friends. These individuals acted as *communication partners* by relaying important 359 information which may otherwise be missed in conversation. Several participants also 360 reported that the hearing in their 'good' ear appeared enhanced since the onset of their 361 hearing loss.

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363 Coping strategies

Coping strategies were developed by participants to aid engagement and participation in everyday situations. These strategies were primarily a result of self-learning and adaptation due to a *lack of formal information* and advice from clinicians. Their use of coping strategies appeared to be dependent upon factors including personality traits, social and professional circumstances, and personal attitudes towards hearing loss. *Positioning in a social setting* was regarded as highly important for participants to maximise the signal-to-noise ratio at their

| 370 | better ear and to access visual cues (e.g. lip-reading) to aid their ability to understand speech. |
|-----|--|
| 371 | Participants also highlighted the importance of support from family and friends both in |
| 372 | communicating in challenging listening situations and to help in potentially-dangerous |
| 373 | situations such as crossing a road when they are unable to localise the sound of traffic or |
| 374 | identify the distance of vehicles. |
| 375 | |
| 376 | Participants reported that they do not generally wear hearing-assistive devices. In general, |
| 377 | they did not find conventional hearing aids to be beneficial for their hearing. Consequently, |
| 378 | they felt frustrated that their hearing loss was an invisible condition and some had even |
| 379 | considered wearing a hearing aid solely to remind others of their hearing loss. Those who had |
| 380 | trialled a contralateral routing of signals (CROS) hearing aid (Harford and Barry 1965) |
| 381 | deemed its benefits to be limited and did not persist with its use or use it regularly. Some |
| 382 | participants relied on other technologies to enhance their hearing and listening abilities such |
| 383 | as using subtitles, a speakerphone, a sound-bar for the television, or headphones that can be |
| 384 | manipulated so that all sounds play in one-ear only. |
| 385 | |

386 **Discussion**

The primary aim of the current study was to explore the lasting psychological and social consequences that SSD places on the individual using a technique that attempts to isolate the researchers from the process of selecting topics for discussion (Glaser & Strauss, 1967). It is inevitable that there will be individual differences in how people cope with a health condition such as SSD and the degree to which the condition imposes burden upon them. However, consistency was observed both in the topics that were identified across the interviews (Table 3) and the content of the subsequent discussions, as indicated by the well-defined themes and 394 sub-themes that emerged in the inductive thematic analysis. As only a small number of 395 patients with acquired SSD were consulted in this study, caution should be exercised in 396 generalising the results to the broader population of patients with SSD that encompasses a 397 greater variation in aetiology and duration of deafness than sampled in the present study and 398 also includes those deafened congenitally. However, it is notable that the findings form 399 strong parallels with those of previous studies whose samples differed from that of the current 400 study on some of these factors (e.g. Giolas & Wark, 1967; Sano, 2013; Subramanium et al, 401 2005; Wie et al. 2010). This apparent consistency prompts the conclusion that there are 402 common longer-term psychological and social consequences of SSD that arise among 403 individuals despite differences in their age, aetiology, and duration of monaural auditory 404 deprivation. The current thematic analysis identified recurring consequences that included 405 worry about losing the hearing in the better ear, strong negative emotions including 406 embarrassment and frustration, low self-efficacy, and negative coping strategies such as 407 withdrawing from and within challenging everyday listening situations.

408

409 While one might expect that the effects of SSD would be exclusively negative, participants in 410 the present study were able to identify some positive consequences of their hearing loss. 411 Previous studies investigating the positive aspects of acquired hearing loss have identified 412 major themes including reduced disturbance by unwanted sounds (Stephens & Kerr, 2003), 413 recognition of one's ability to develop successful communication strategies (Manchaiah et al, 414 2015), and benefits of receiving communicative support from others to offload some of the 415 burden that hearing loss imposes (Lockey et al, 2010). These themes capture the positive 416 consequences identified by participants in the present study that included improvements in

the ability to fall and stay asleep, the ability to develop coping strategies in the absence ofadvice from clinicians, and the receipt of help from others.

419

420 The extent of the negative psychological and social consequences of SSD may perhaps be 421 surprising given the fact that these individuals have access to one largely unimpaired ear. 422 However, this apparent incongruence is compatible with the notion that it is not straightforward to predict an individual's 'hearing handicap'¹ based upon the level (as 423 424 measured by the audiogram) or lateralisation of hearing loss alone (Hallberg et al, 2008). A 425 hearing loss that is confined to one ear only cannot therefore be assumed to have only 426 minimal effects on health and well-being (Wie et al, 2010), which may be influenced strongly 427 by factors beyond the audiogram such as whether the onset of a hearing loss is gradual or 428 sudden (Sano, 2013). In fact, some aspects of the psychological and social consequences of 429 SSD were similar to those reported by individuals with mild and moderate levels of hearing 430 loss (Heffernan et al, 2016) and those with severe-to-profound losses (Mäki-Torkko et al, 431 2015). For example, individuals with hearing loss of varying degrees and laterality 432 consistently report withdrawing from and within busy social situations, feeling negative 433 emotions as a result of their hearing loss, and experiencing participation restrictions that have 434 a tangible impact on their everyday life. The burden of having to rely on other people to 435 communicate effectively was reported by the current participants but it has also been noted in 436 individuals with milder forms of hearing loss (Lockey et al, 2010). However, the present 437 study also suggests that the burden imposed by SSD is highly situation specific whereby an 438 individual's capacity to integrate and participate in a given situation may be altered by even a

¹ In this context, hearing handicap refers to the extent to which their hearing loss affects their behavior and wellbeing (Ventry & Weinstein, 1982).

small change in the listening environment. For example, participants reported having little or
no difficulty conversing with one person in a quiet room but also reported that they would
experience considerable difficulty with the addition of even low levels of background noise
or if even one other person spoke at the same time.

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444 Although the CROS aid is the standard audiological intervention for those with SSD in the 445 UK where this study was conducted (Baguley et al, 2006; Kitterick et al, 2014), only one 446 participant in this study reported using one consistently but only in a specific listening situation (watching television) and reported little or no benefit from doing so. The uptake and 447 448 use of CROS aids has been suggested to relate to the motivation of the patient to take up 449 technological support (Harford and Barry, 1965) and also to the cosmetic appearance and 450 discomfort from wearing an aid that may occlude, or be perceived to occlude, the normal-451 hearing ear (Ryu et al, 2015). Uptake and usage may also be affected by a mismatch between 452 patient needs and device capabilities. However, approximately half of the participants had 453 never been offered a CROS aid and some of those individuals were completely unaware of 454 the intervention, suggesting that provision of CROS devices may also vary geographically in 455 the UK. This apparent lack of provision and uptake of hearing-assistive devices (e.g. CROS, BCHD and CI) is particularly problematic in light of existing evidence for the beneficial 456 457 effects that they can have on quality of life by alleviating listening difficulties (Desmet et al, 458 2012; Hol et al, 2010; Kompis et al, 2017; Mertens et al, 2015; Ryu et al, 2015; Saliba et 459 al, 2011; Schrøder et al, 2010; Wesarg et al, 2013; Távora-Vieira et al, 2015) and increasing 460 overall health and well-being (Arndt et al, 2011).

461

462 The fact that the burden imposed by SSD is not immediately obvious from the audiogram 463 alone and is not likely to be apparent in the quiet confines of the clinic may explain, at least 464 in part, why no participant in the present sample reported being referred for counselling or 465 offered non-technological forms of support or why so few appeared to have been offered 466 devices such as CROS aids. In particular, participants suggested that they would have 467 benefitted from receiving information about the long-term implications of their condition, the 468 potential benefits and limitations of available interventions and devices (e.g. CROS, BCHD 469 and CI), and advice on techniques and strategies for self-management. Participants also 470 reported that their coping strategies were a result of self-learning developed from years of 471 experience of living with their hearing loss rather than based on advice from a clinical 472 professional. It would therefore seem appropriate for the clinical management of individuals 473 with SSD to incorporate information-giving (Fig. 1, shaded decision nodes) to target the 474 counterproductive strategies that were identified by participants in the present study; i.e. the 475 sub-themes of withdrawing *within* situations (where the individual was motivated to attend 476 despite their listening difficulties) and withdrawing from situations (where participation was 477 considered counterproductive to their well-being). The provision of this information could 478 provide an opportunity to discuss the chronic symptoms and implications of the condition 479 ('lack of formal information' sub-theme), reduce any negative emotions associated with 480 engaging in social situations ('social interactions' sub-theme), and aim to develop motivation 481 for engagement and uptake of hearing-assistive devices such as CROS aids or BCHDs 482 ('hearing-assistive devices' sub-theme; Ferguson et al, 2016) (Fig. 1, 'Motivated to 483 participate?'). It could support individuals to develop realistic expectations about their ability 484 to integrate and participate with others ('social stigma' and 'self-stigma' sub-themes), 485 encourage positive beliefs around their ability to participate ('low self-efficacy' sub-theme; 486 Bandura, 1977), and ensure that individuals understand what benefits their hearing-assistive

devices can provide and in what situations ('hearing-assistive devices' sub-theme; Fig. 1,
'Appropriate expectations?'). Finally, clinicians could deliver advice on developing positive
coping strategies such as how to position oneself within a social situation to maximise
audibility ('positioning in a social setting' sub-theme; Fig. 1, 'Aware of coping strategies?').
However, this advice would have to be modified to account for the use of rerouting devices
such as CROS aids and BCHDs; their use may conflict with listening strategies that would
otherwise be beneficial such as positioning unwanted noises toward the deaf ear.

494

495 The present qualitative analysis leads to the conclusion that SSD imposes a substantial degree 496 of burden across multiple domains of health that can lead to negative effects on psychological well-being and restrictions on social participation. Almost 50 years ago, Giolas & Wark 497 498 (1967) proposed that the clinical management of individuals with SSD should address these 499 negative effects and there is now a large body of evidence for how hearing-assistive devices 500 can alleviate listening difficulties and support participation in everyday life (Finke et al. 501 2017b; Kitterick et al, 2016; Peters et al, 2015). However, patients still identify a lack of 502 clinical support, which the present qualitative analysis suggests could be addressed through 503 information giving. The integration of this additional support into their clinical management 504 plan could help these individuals to develop, manage, and adopt effective coping strategies 505 and maximize take-up and use of hearing-assistive devices.

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689 Figure captions

- 690 **Figure 1:** Flow chart demonstrating the main coping strategies that participants reported
- 691 using in social situations and the sequence of events that prompt the use of a given
- 692 strategy; i.e. positive engagement, withdrawal from situations (social isolation /
- 693 avoidance), or withdrawal within situations (introversion). Events are indicated using
- 694 rectangles and decisions are indicated using diamonds. The potential influences of
- 695 counselling on behavior are indicated by the shaded decision nodes.

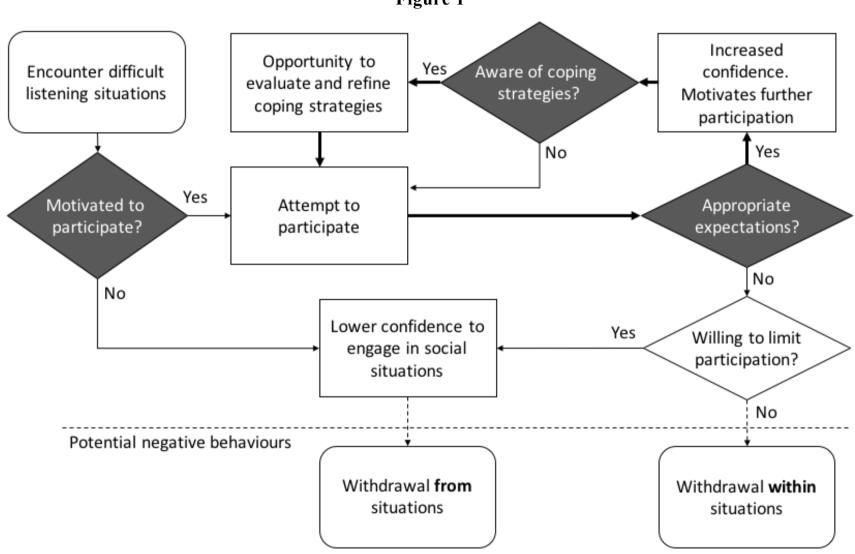


Figure 1

| Participant | Gender | Age | Employment status | Onset | Aetiology | Duration | Tinnitus | Reported |
|-------------|--------|-----------------------|-------------------------|-------------|---------------------|--------------------|----------|-------------|
| ID | | | | | | | | device use |
| P1 | female | 67 | retired | sudden | idiopathic | 23+ years | yes | Hearing aid |
| P2 | male | 71 | retired | sudden | surgery for | 8 years, 5 months | yes | CROS |
| Ves | | vestibular schwannoma | | | | | | |
| P3 | female | 53 | self-employed part time | progressive | meningitis | 26 years, 9 months | yes | None |
| P4 | female | 68 | retired | sudden | idiopathic | 5 years | no | None |
| P5 | male | 66 | retired | progressive | age-related decline | 28 years | yes | None |
| P6 | female | 56 | employed full-time | sudden | idiopathic | 2 years | yes | None |
| P7 | male | 40 | employed full-time | sudden | surgery for | 6 years, 4 months | yes | None |
| vestibular | | vestibular schwannoma | | | | | | |
| P8 | male | 37 | employed full-time | sudden | idiopathic | 1 year, 1 month | yes | None |

Table 1: Demographic information for the individuals with single-sided deafness that participated in the interviews.

| Activity | Description | | | | |
|---|--|--|--|--|--|
| Introduction | The facilitator gave an overview of the research question, the motivation for asking the question, and presented the structure | | | | |
| | of the activity. Participants were able to ask questions before proceeding on to the first activity. | | | | |
| Topic Participants were provided with red and green 'topic' cards and asked to fill in the cards without conferring wi | | | | | |
| generation | red (or green) cards captured situations in which their hearing loss created (or did not create) difficulties for them or had | | | | |
| | negative (or positive) consequences. To ensure that the topic generation exercise captured all relevant issues, no matter how | | | | |
| | sensitive, each card included a box that participants could tick to indicate that they did not wish the topic to be discussed with | | | | |
| | the other participants. | | | | |
| Break | The facilitator and co-facilitator grouped cards that contained similar topics for discussion (e.g. localising sounds, | | | | |
| | communication, social impacts, psychological effects, etc.). | | | | |
| Semi-structured | Participants were handed back their responses cards. The facilitator read out each identified topic in turn and proceeded to | | | | |
| discussion | ask questions to seek clarification or to gain a better understanding of the situation or consequences linked to each topic. This | | | | |
| | process was repeated until all topics and responses had been discussed. The facilitator encouraged all participants to | | | | |
| | contribute to each topic of discussion to ensure all views were captured. The semi-structured discussion ended when the | | | | |
| | participants felt that all topics written on their cards had been discussed. | | | | |
| Unstructured | An open-ended question was posed by the facilitator to capture any other situations or consequences related to their hearing | | | | |
| discussion | loss that had not yet been discussed. Any additional topics were discussed as in the semi-structured discussion. | | | | |
| Debriefing | Participants were thanked for their involvement, reminded of the purposes of the study, and informed that the results would | | | | |
| | be provided to them when available. Before leaving, participants were provided with an information sheet containing the | | | | |
| | contact details of national charities and support organisations related to hearing loss and well-being and were informed to | | | | |
| | contact their family doctor with any concerns about their hearing, health or well-being. | | | | |

 Table 2: Sequence and description of activities in each of the three interviews.

| Interview 1 | Interview 2 | Interview 3 |
|---|--|--|
| P3: "Group discussion in a room with background noise e.g. music,TV or other conversation going on." | P2: "Group conversations, particularly in social settings where people, understandably, talk over each other." | P7: "Group conversations i.e. when there is background noise." |
| P5: "Need to position myself on the corner of a table in order to hear as much as possible with my good ear." | P2: "Concerts – need to choose sides." | P4: "Joining a meeting late and not being able to select a seat which aids my SSD." |
| P5: "I have no appreciation of music in stereo. This is very noticeable when I recollect exactly what a particular piece of music or a play with sound effects was like when I could hear with both ears." | P6: "Music - I miss stereo sound." | P8: "I miss stereo music with headphones." |
| P5: "Knowing which direction traffic is approaching from." | P6: "Direction - If I'm walking across a road I have to rely on my eyes to know where a car is coming from." | P7: "Can't tell which direction sound is coming from." |

Table 3: Examples of similar topics identified by patients in the 'topic generation exercise' across the three group interviews.

List of Supplemental Digital Content

Supplemental Digital Content 1: Table listing the individual topics identified by participants themselves using the Critical Incident Technique within each category. Pdf

The raw unedited text from the topic cards completed by participants during the 'topic generation exercise'. Similar negative and positive topics have been grouped together within each interview.

Interview 1: Negative consequences / difficulties Concern over loss of hearing in good ear. Fear of anything happening to the other 'good' ear. Feeling isolated, frustrated and left out of conversations - only hear snippets of what is said and lack of confidence to join in. Feel like people think you are dull or have nothing to say. If someone approaches on my deaf side and I can't see them it makes me jump. Knowing which direction traffic is approaching from. Discerning direction of sound. E.g. traffic noise or of who is speaking where. Having to go around in circles to ascertain the direction of a noise. Unable to tell where family members are in the house if they are not in the same room as me. My first question is always 'where are you?' '1'm here' does not help. Need to position myself on the corner of a table in order to hear as much as possible with my good ear. As my left ear is profoundly deaf, listening to the radio in a car is harder on the passenger side than on the driver side. Also hearing a person whilst driving is difficult. Other people not being sympathetic. People shouting when I tell them I have a hearing loss or don't bother trying to talk to you. Lack of willingness to engage. Other people exasperated because you can't hear. Networking situations at work, particularly with people who don't know me and don't understand about my hearing disability. People will repeat something once, but do not want to repeat it again if asked. Eventually they talk to someone else because it is less of an effort for them. If I'm at a table at a formal or informal dinner I have to notify the person on my left that if they say something I won't hear them. This usually ensures that they do not make any effort to talk to me. Trying to get workplace to make reasonable adjustments and having to fight. Positioning myself at work in open plan office - need to be in a corner with colleagues to right and in front of me. Convincing people of this and having to fight for the position is frustrating. My ex-boss who used to say 'pardon?' every time I said I had a hearing loss (his little joke) until someone pointed out it was not funny. Airports / train stations can't hear announcements. Noisy young children - can't hear what other people are saying. Group discussion in a room with background noise e.g. music, TV or other conversation going on. One to one discussion in a noisy environment. E.g. noisy pub / restaurant. I can do this but it is tiring. Sometimes ask to move e.g. in corner or against wall. Syndicate groups in e.g. a work conference if more than one group in the same room. Certain social occasions e.g. meal in busy restaurant with lots of chatter - strain to follow conversation and person on deaf side. Effort to concentrate on them - fatigue. If someone is on my left and actually makes an effort to speak to me I have to turn my ear and cup my right ear. This is very fatiguing on a long airplane flight. I have no appreciation of music in stereo. This is very noticeable when I recollect exactly what a particular piece of music or a play with sound effects was like when I could hear with both ears.

I have continuous tinnitus in my left ear due to cochlear damage caused by an infection following a stapedotomy. Other SSD impaired people may have the same problem. Check for cause of SSD if it is a problem with the cochlear they will probably suffer with tinnitus.

I have no balance mechanism due to my left ear. This could also apply to others whose loss of hearing is caused by cochlear damage.

Interview 1: Positive consequences / no difficulty

One to one discussion in quiet environment.

Group discussion in quiet room where only one person talks at once.

Group conversation in a quiet room is OK.

Group discussion in a quiet room where only one person talks at once.

Sleeping – Sleep on good ear if there is noise.

Being in a nosy environment if I'm with someone e.g. a friend who understands.

Music.

Tinnitus doesn't bother me any more even though it's there all the time. I tune out from it.

TV usually OK.

TV is ok as it is not usually in stereo.

Telephone usually OK.

Telephone is OK with hearing ear.

Telling people I have a hearing disability.

Interview 2: Negative consequences / difficulties

Direction - If I'm walking across a road I have to rely on my eyes to know where a car is coming from.

Direction - When I'm driving - where is the ambulance.

Direction - I can't tell where somebody is. If my husband says 'I'm here' I can't tell where he is. He has to say 'I'm in the kitchen'.

Direction - If I drop something I've no idea where it rolls to.

No directional information.

Frustration. Where is the squeak coming from in the car?

In the car. When I drive, my wife is on my deaf side.

Music - I miss stereo sound.

Sound 'topography' is 'flat' so bird song etc. is lacking (possibly a directional problem?)

Concerts - need to choose sides.

Have difficulty in noise (crowded) situations and find I just hear a general hubbub of noise and have to be very close to somebody to hear what they are saying.

At work - meetings are often difficult if too many people talk at once, or especially if there is a phone link to another global office. I have to make sure I sit close to the speaker.

Group conversations, particularly in social settings where people, understandably, talk over each other.

I work in an open-plan environment and find it difficult to hear some people (especially those who speak quietly). I have to go into a quiet room to phone somebody otherwise I have difficulty distinguishing their voice over the voice of others.

Confusing 'live' sound with that which is on the TV & radio.

Telephone - I want to hold the phone in my right hand, but I often want to jot down a note and I'm right handed.

Telephone - Can't switch ears. If my arm gets tired it's difficult. In a public situation if somebody wants to get past me and they talk into my left (bad) ear saying 'excuse me' they often think I'm rude and ignoring them.

I'm more antisocial, as I find conversations more difficult. It seems that 'muzak' is more often found in restaurants, waiting rooms etc.

Withdrawal of my active interest. Previously I might seek the sources of an unexpected sound, now, less often.

I use a 'wake & shake' alarm clock, because I sleep mostly on my good ear. However, I worry about not hearing other sounds at night - like my burglar alarm going off.

I find I'm saying 'excuse me' a lot of the time and people have to repeat what they say.

Cycling – balance.

Tinnitus possibly worse, very one-sided.

Interview 2: Positive consequences / no difficulty

I've found I can lip read better than most people.

I've realised how good the hearing is in my right ear and there are millions of worse things a person can have.

I can switch of noise more easily sometimes at work when I'm concentrating.

Sleeping - I can put hearing ear into the pillow.

Somehow, I hear things I'm not intended to hear. Change in tone on speaking 'sotto voce'.

Interview 3: Negative consequences / difficulties

Background noise - find it hard to hear as just one ear trying to deal with all the 360 degree sound.

Completely ignore people on my deaf side if they speak and there is any background noise.

Parties are a nightmare (but sometimes I am quite glad of an excuse to opt out).

Group conversations i.e. when there is background noise.

Very difficult to interact in groups larger than 2-3 people.

Conversations within a group socially.

Had difficulty with meetings at work.

If more than one person talks at once I give up and have to tell whoever is speaking to wait.

One to one conversations on 'deaf side' in a noisy environment.

Speaking to my son, when I pick him up from school (he's 7), so therefore small, with background noise I can't hear what he is saying.

Talking on the phone if there is background noise.

Telephone- have to use my other ear now.

Had difficulty taking telephone calls at work.

Listening whilst on the phone.

Talking on the phone for a long period of time as arm aches and can't swap ears.

Hearing bicycles / people behind me when out walking.

Hearing people who are talking behind me.

Again - not knowing where sounds are coming from, crossing the road takes much more concentration, is more dangerous.

No idea where sounds are coming from - someone calls me, I have no idea where to look. The mobile phone goes and I don't know where to go to answer it.

Can't tell which direction sound is coming from.

Can be slightly concerning when cycling as can't always hear where cars are coming from.

Can't hear when I am a passenger in a car, and I have to twist my head around.

Have to continually turn my head to one side to listen to noises/ conversation in front of me. Can result in a sore neck.

Constantly have to change the side I walk when walking/talking to people even after continuously telling people I need to be on their right they don't listen.

I always position myself on the outside of a group as it is impossible to be in the middle and try and keep up with what's going on.

Finding good places to sit when eating with friends.

Joining a meeting late and not being able to select a seat which aids my SSD.

It can be tiresome having to tell total strangers why you don't hear them or why they have to talk on my good side. In restaurants / on trains/ on planes.

A lot of the time I can phase out thinking about the problems but sometimes it feels impossible that I must be like this for the rest of my life.

Periodic depression.

A feeling that no-one understands and that they would only take any interest if I was deaf completely.

Difficult hearing shop assistants - I feel stupid.

Sometimes family forget and I get frustrated when I can't hear - it feels very unfair.

Getting people to understand that I can't hear on the left side so please talk to me on my right.

I don't feel part of large gatherings and no longer am able to enjoy large socials.

I always avoid large groups and my socialising is almost non-existent because of this.

I hate to be thought of as rude for ignoring people on my SSD side who aren't aware.

Terror about any problem with my good ear.

The unknown 'SSD' causes, etc. No answers from medical professionals, sometimes dismissive, left in the dark.

Questions' about further recurrence, further deafness.

Will my hearing deteriorate in the right ear?

Enjoyment of music - now only in mono, some distortion at certain levels.

I miss stereo music with headphones.

Distorted hearing at certain volumes.

I find it exhausting listening to someone when there is background noise.

I get much more tired from the extra effort it takes to concentrate and spend more time lying down.

Tinnitus - since hearing loss night and day – awful.

Am aware that I have some tinnitus in both ears, but with the one with no hearing it is intense and sometimes makes me feel desperate.

I can feel very dizzy if walking in crowds and noisy environments (possibly not as a result of SSD but because of acoustic neuroma surgery).

I have some dizziness left over from labrynthitis, but I am not sure if this is made worse by the deafness - affecting my balance.

Interview 3: Positive consequences / no difficulty

Not any real problem watching TV if it is just me in the room and no other noise.

Ear plugs to cancel out noise last twice as long.

If trying to sleep when there is noise I can lay on one side and not hear the surrounding noise.

I'm not kept awake when the neighbours have parties.

I was only the only one in the house who slept well when my little granddaughter was born.

I can't hear my husband snoring.

Better with one-to-one conversations.