

1 **Managing employees with dementia: a systematic review**

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20

21 **Abstract**

22

23 **Background:** The experience of developing dementia while in employment has been explored from
24 the point of view of the employee, but less is known about the perspectives, experiences and needs of
25 employers.

26

27 **Aims:** To review systematically literature about the management of employees who develop dementia
28 whilst in employment.

29

30 **Methods:** Databases searched included MEDLINE, EMBASE, PsycINFO, CINAHL, BNI, ABI
31 Inform, ISI Web of Science, Open Grey and dementia journals database; 44 documents were
32 identified for inclusion in the review: 22 journal papers, one PhD thesis and 21 articles, reports and
33 webpages from the grey literature. As all documents were qualitative in nature a thematic synthesis of
34 their content was undertaken.

35

36 **Results:** Three main themes and ten sub-themes were identified. The main themes concerned early
37 presentation and identification in the workplace; reasonable adjustments for people with working age
38 dementia; and the provision of information to raise awareness and facilitate informed choice. The
39 evidence suggested that there is a lack of awareness about working age dementia and that this may
40 impact negatively on employees. Guidance for employers offered suggestions for good practice.

41

42 **Conclusions:** Guidance for employers is increasingly available although it rarely refers to the
43 evidence base. There is a need for future studies that explore the effectiveness of guidance and
44 training initiatives for employers. Examples of good practice where employees with dementia have
45 been well supported in the workplace and who have been able to leave the workforce with dignity,
46 would be helpful.

47

48 **Key words:** working-age dementia; systematic review; employment practices; occupational health

49 **Introduction**

50 When dementia affects people between 30 and 65 years old, it is referred to as ‘presenile’, ‘early
51 onset’ or ‘working-age’ dementia. Most individuals in this age group are likely still to be employed
52 when symptoms first appear [1] and may experience difficulties at work due to mild cognitive
53 impairment (MCI) for several years before formal diagnosis. In 2014 it was estimated that there were
54 over 42,000 people with working-age dementia in the UK [2]. A review of worldwide studies
55 suggested that the prevalence in the general population ranged from 0-700 per 100,000 [3]. Although
56 the risk of dementia rises steeply with age, onset can occur in mid-life.

57

58 To date, there has been relatively little research on employment experiences of people with working
59 age dementia, and no systematic reviews on this topic. Some research has focused on the work-related
60 experience of people with dementia [4,5] and some on the social and economic consequences of their
61 exit from the labour force [6,7,8]. These identify the difficulties experienced by people with working-
62 age dementia. However, we also need to understand the perspectives, experiences and needs of
63 employers. This article seeks to address this gap, by systematically reviewing the literature on the
64 management of those who develop dementia whilst in employment.

65

66 In the UK, the Equality Act (2010) obliges employers to provide reasonable work adjustments for
67 people living with conditions that qualify as a disability. Other jurisdictions have similar legislation,
68 such as Australia (Disability Discrimination Act) and the USA (Americans with Disabilities Act).
69 However, little is known about how these legal requirements are met with regard to dementia. The
70 need for such knowledge will increase as more people work past the age of 65 [9]. This will help
71 employers to put appropriate plans in place, and to minimise the reported difficulties experienced by
72 employees with dementia and their families. Therefore, our aim was to conduct a systematic review of
73 the published literature, scientific studies and other types of publication available on-line (the grey
74 literature), to develop further our understanding of current research knowledge and employer practice
75 in relation to the management of employees who develop working-age dementia.

76

77 **Methods**

78 This systematic review followed guidance outlined by the Centre for Reviews and Dissemination
79 [10]. Literature searches were conducted from September to October 2016. Ethics approval was not
80 required as this was a systematic review.

81

82 All types of study design were included in the original search. These included both quantitative and
83 qualitative study designs (such as those involving focus groups, interviews or non-participant
84 observation). Participants were adults aged 18 and over who had a diagnosis of dementia or mild
85 cognitive impairment. Studies were excluded if focussed on Parkinson’s disease or other neurological
86 disorders. Any reported occupational or employment-related outcome or topic was considered
87 relevant. The focus was solely on the employment of the person with dementia; studies that focused
88 on employment outcomes for carers were excluded. The studies could be performed in any country,
89 but papers were restricted to the English language. There was no limitation on the time period of
90 interest. Any reported work-related outcome or topic was considered relevant.

91

92 Literature search strategies were designed to identify all relevant studies regardless of publication
93 status. Search strategies were developed for each database. Keywords for ‘dementia’, ‘employment’
94 and ‘early onset’ and ‘policy’ were the controlled terms and text words used in each database. The
95 following were searched from inception to 1st July 2016: MEDLINE (Ovid); EMBASE
96 (www.embase.com); PsycINFO; CINAHL; BNI; ABI Inform; ISI Web of Science; Open Grey
97 (<http://www.opengrey.eu/>); Google Scholar; dementia journals database; and individual websites (see
98 Appendix 1 for a complete list and search strategy).

99

100 [Figure 1 here]

101

102 The flow chart for the identification of documents is shown in Figure 1. Screening of titles was
103 performed independently by two reviewers and non-relevant references and duplicates were
104 discarded. In the second level of screening, abstracts of potentially relevant references were read.

105 Those that did not meet the inclusion criteria were excluded. In cases of disagreement, the full article
106 was obtained, independently inspected, and inclusion criteria applied by two reviewers. Disagreement
107 was resolved through discussion and checked by a third reviewer where necessary. Justification for
108 excluding articles from the review was recorded. In total, 69 documents from the scientific and grey
109 literatures remained. Following data extraction including full screening of all 69 documents, a further
110 22 were excluded for not including relevant material and three excluded as duplicates. The remaining
111 44 studies and articles were of seven broad categories (see Table 1).

112

113 [Table 1 here]

114

115 For quality assessment of papers, the identification of criteria that are relevant to the specific review is
116 advocated. As the journal papers identified in this review were all qualitative, we used the Critical
117 Appraisal Skills Programme (CASP) tool. This tool was used to conduct quality assessments of
118 articles describing the collection of primary research data; quality assessment scores are presented in
119 Table 2.

120

121 [Table 2 here]

122

123 To enable qualitative synthesis, all articles were analysed using thematic analysis [11,12] in order to
124 integrate their content. This involved open coding to develop ‘descriptive’ themes. The constant
125 comparison method was used to develop the themes which are further interpreted to yield ‘analytical’
126 themes.

127

128 **Results**

129 Three over-arching themes and ten sub-themes were identified (Table 3) and are described below.

130 [Table 3 here]

131

132

133 The first over-arching theme related to the early presentation and identification of dementia in the
134 workplace. The literature highlighted the likelihood that a substantial number of people working are
135 unaware of their developing condition. This was thought to be partly due to that fact that delays in
136 diagnosis are particularly common for people with working age dementia [13]. Four sub-themes were
137 identified: hiding difficulties; early symptoms; from symptoms to diagnosis; interactions with
138 employees

139

140 The first sub-theme was 'Hiding Difficulties'. Many articles described how employees may often
141 conceal their symptoms [4]. They may try to 'restrict' their activities when they experience new
142 difficulties [14] or may not acknowledge difficulties as they go through a period of denial. It was
143 noted that an employer (as a party other than an employee's partner or family member) can play a key
144 role in persuading a person with suspected dementia to seek specialist advice [15].

145

146 Employees are likely to self-manage their symptoms as a first response rather than discuss concerns
147 with their employers [4]. This can contribute to delays in diagnosis and can lead to pressure to
148 improve on faltering performance at work [1]. In turn, this may lead to dismissal where performance
149 fails to improve [16].

150

151 Even when diagnosed, employees may wish to conceal their diagnosis. Many fear the reactions of
152 colleagues and employers, that they might not be able to continue working, that they would be bullied,
153 or be discriminated against if looking for a new job [13,17,18]. However, there were also reports of
154 colleagues 'rallying round' employees when they learn about their diagnosis [19].

155

156 The second sub-theme was 'Early Symptoms'. The articles described how symptoms of working age
157 dementia are more varied than those typically observed in dementia later in life. Less common forms
158 of dementia, such as frontotemporal dementia, are more frequent in those with working age dementia
159 than in older groups. And although in this type of dementia, memory loss is common, other
160 presentations such as changes in personality and behaviour can be involved [1,20]. These may be

161 associated with, for example, to alcohol abuse, gambling or domestic conflict. These more varied
162 presentations can also contribute to delays in obtaining a correct diagnosis.

163

164 Some of the symptoms most likely to be noted by employers are memory-related: such as difficulty
165 remembering names [4,14,21,22,23] and missing appointments [20,21,24]. Employees are noted as
166 compensating for such forgetfulness via strategies such as keeping lists, calendars and clocks in front
167 of them at work [22] or spending increasing time planning and organising their tasks [4].

168

169 Changes in various cognitive skills are commonly reported, such as disturbance in language [22],
170 constant repetition during conversations [20,23], and reduced numerical ability [23]. Difficulties in
171 managing cash and doing accounts have been reported. Other cognitive impairments include
172 difficulties using logic or judgement and dealing with the abstract [22].

173

174 Psychological symptoms are frequently manifested. Depression is common, as are associated
175 behaviours and emotions such as reluctance to engage with others, increased agitation, irritability or
176 apathy [22]. Anxiety is also common [23]. Some employees initially attribute such symptoms to
177 work-related stress [25]. Other psychological symptoms include delusions and hallucinations [26].

178 In one study of people with working age dementia, aggressive behaviour was reported in 50% of
179 participants [23]. Most of this behaviour was verbal aggression, but some employees became
180 physically aggressive. Some risk losing their jobs due to 'unacceptable behaviour' [23].

181

182 The decline in ability to perform to previous standards is one of the signs of working age dementia
183 [20,23]. This can include: difficulty adjusting to new tasks [4], deficits in dexterity for complex tasks
184 [22], multiple physical health complaints, increased absence from work [21,22] and a change in
185 attitude to performance, for example changing from being a perfectionist to having a "that'll do"
186 attitude [25]. Unexplained reductions in performance and the inability to make improvements
187 demanded by employers often lead to dismissal for people who have yet to be diagnosed [16].

188 In the grey literature, the Australian Government's Job Access website [27] noted the following list of
189 symptoms that may become apparent at work: forgetting appointments or meetings, confusion about
190 time and place (e.g. forgetting the day of the week or being unable to identify where they are),
191 difficulty finding the right words, difficulty concentrating, poor or decreased judgment (e.g.
192 misjudging distance when driving), misplacing things, changes in personality or behaviour (rapid
193 mood swings, or becoming confused and withdrawn), uncertainty about making important decisions,
194 and losing confidence.

195

196 The third sub-theme was 'From symptoms to diagnosis'. The literature described how once symptoms
197 are acknowledged, the confirmation of a diagnosis of dementia can be a long and difficult process.
198 The average person diagnosed with working-age dementia has been in their current job for at least
199 nine years [28]. It frequently takes more than a year to reach diagnosis [14]. Low diagnosis rates are
200 partly due to the condition being relatively uncommon in people under 65 and partly due to symptoms
201 being mistakenly attributed to other conditions such as stress or depression [13]. Undergoing
202 investigations for dementia can itself be a stressful experience, and can be exacerbated where an
203 employer fails to deal with the situation appropriately [28].

204

205 Diagnosis of working age dementia is challenging [14], largely due to the need to exclude other
206 aetiologies. Referral to specialist units, such as memory clinics [29,30], is usually required for a
207 correct diagnosis. Healthcare professionals often administer a range of physical (blood tests and
208 neuroimaging) and psychological tests in the assessment of possible dementia that are not suitable for
209 routine use in the workplace [4,22,25,26,31,32].

210

211 Despite their fears beforehand, individuals with working age dementia do not report regretting having
212 knowledge of their diagnosis. They often find that diagnosis helps them make sense of their
213 experiences and make plans about how long they want to carry on working and explore what support
214 their employers can provide [13]. Early identification can also allow time for handover of knowledge
215 and responsibilities to colleagues and successors [33].

216

217 The fourth sub-theme was ‘Interactions with Employees’. Advice on how employers should approach
218 and interact with an employee whom they know, or suspect, to have working-age dementia, was
219 offered in a number of articles. It included: sensitively asking employees if they have noticed they are
220 having memory or planning problems [20,33]; asking whether they have been having similar
221 problems at home, and whether these could be discussed with family members [33]; urging employees
222 to get a medical evaluation from a specialist in memory loss [33]. A careful approach, expressing
223 concern for the individual employee, is recommended [20], as this can help minimise negative
224 consequences triggered by a diagnosis such as anxiety, depression and suicidal ideation [25].
225 Participants in one study reported that their employers lacked empathy [30]. Experiences of traumatic
226 cessation of employment and harsh treatment by employers were reported in several studies [4,16,30].

227

228 In 2015 the UK’s Alzheimer’s Society published guidelines for supporting employees in the early
229 stages of dementia [21]. They describe six workplace scenarios and suggest ways to respond in each,
230 emphasising the importance of good communication throughout. This may include checking relevant
231 policies and seeking advice from Human Resource (HR) or Occupational Health (OH) professionals.
232 An open and honest dialogue is encouraged, and one where the employee is given an overriding
233 message of support, recognising that timing and extent of disclosure is ultimately the employee’s
234 decision. Notes of discussions and plans should be maintained.

235

236 The Dementia Engagement and Empowerment Project (DEEP) [34] is an initiative that seeks to bring
237 together people with dementia in the UK with the aim of affecting change in services and policy.
238 Their website also provides advice for employers, recommending that they have clear policies about
239 how they can provide support. Where employees have a diagnosis of dementia, DEEP recommends
240 that employers should outline to employees the support that is available, encourage employees to be
241 aware of their symptoms and how they might affect them at work and explain the procedures that
242 need to be followed. They also note that employers need to be flexible and compassionate about
243 employees’ needs to attend medical appointments [34].

244

245

246 The second over-arching theme identified from the literature related to the reasonable adjustments that
247 allowed people with dementia to remain in work for some period of time. Within this theme four sub-
248 themes were identified: the desire to stay in work; typical adjustments; the process of making
249 adjustments; reported experiences of reasonable adjustments.

250

251 The sub-theme on the desire of people with working age dementia to stay in work was reflected in
252 several journal articles, as was the importance for employers to facilitate this. People with working
253 age dementia described the importance of remaining independent, using their skills and abilities and
254 maintaining meaning and purpose through working life [16,18,30]. When people with working age
255 dementia were asked about their needs, their overwhelming desire was for purposeful activity and the
256 opportunity to remain in employment for as long as possible [16]. One study highlighted the shock
257 associated with the prospective loss of employment for these employees and the future they had
258 predicted for themselves [19].

259

260 Many studies explored the impact of job loss. There can be emotional and psychological
261 consequences to giving up work or being forced to retire [35] such as devastating impacts on self-
262 esteem and self-worth [26]. All participants with working age dementia in one study reported that
263 leaving work had affected their families and their relationships, and for some that it caused financial
264 hardship [4]. This highlights the important role of employers in enabling employees to remain in
265 work for as long as both parties find possible and desirable.

266

267 A second sub-theme described the typical adjustments made for someone with dementia in the
268 workplace. Establishing structure and routine is important [35] and can be supported by calendars,
269 lists, diaries and keeping such items in a consistent location. Using smart devices to provide timely
270 reminders of meetings, tasks and deadlines can help [36]. The introduction of disability leave,
271 working from home, flexible working or redeployment to a new role has also been suggested [21].

272

273 Health and safety is a primary concern for employers. Guidance advises that it should be a priority to
274 determine whether the condition presents such problems for employees themselves or others
275 [20,33,37], and where health and safety risks are high, adjustments should seek to reduce those risks
276 for the employee with dementia and/or other staff [21].

277

278 Co-workers may also need to be involved in accommodating colleagues with working age dementia
279 [33]; for example, when making adjustments to work schedules or arranging meetings for times when
280 such employees are likely to be at their best [20].

281

282 Campaigning organisations and charities encourage employees to ask their employers for workplace
283 adjustments [38,39]. Table 4 summarises the advice on reasonable adjustments described by UK's
284 Alzheimer's Society [37,40], Australian Government Job Access website [27] and Alzheimer's
285 Australia [39].

286

287 [Table 4 here]

288

289

290 The process of making adjustments was identified as a third sub-theme relating to reasonable
291 adjustments. It is reported that a sense of control and autonomy is important for a person with
292 working age dementia [25] and that it is helpful if the process of making adjustments is a
293 collaborative one, involving both employer and employee [4,20,25,33]. Open discussion may help to
294 prevent changes in job role from feeling punitive [4].

295

296 It is acknowledged that general guidelines about how to manage the work situation of a younger
297 person with dementia are difficult to develop and therefore a case-by-case approach, based on
298 consensus between key stakeholders and the employee should be adopted [23,41]. Young Dementia
299 UK [42] note that the involvement (with the employee's consent) of the employee's GP or consultant

300 can help employers assess specific difficulties and to decide on tasks employees can continue to do,
301 tasks they may need to approach differently, and tasks that they may need to relinquish. The potential
302 for helpful advice from occupational therapists and psychologists was also highlighted: for example,
303 in assessing other (non-task specific) demands in the workplace and the impact on other aspects of the
304 employee's mental health. The importance of regular review is noted [21].

305

306 In the UK, the Alzheimer's Society [17] encouraged employers to adopt good employment practices
307 that support people with dementia to continue to work after a diagnosis. DEEP [34] also highlights the
308 processes and practices that employers should adopt when making adjustment. These are summarised
309 in Table 5.

310

311 [Table 5 here]

312

313 The final sub-theme related to reasonable adjustments concerned the reported experiences of those
314 with working age dementia. The research studies reported that many people with working age
315 dementia have experiences that are far from what is advised in the guidance described above. In cases
316 reported by Chaplin & Davidson [4], none of the participants said that they were offered any
317 reasonable adjustments to their work role after diagnosis. They also reported a lack of consultation
318 and felt that there was no real will in the workplace to find a more suitable job or acknowledge their
319 remaining skills. Similarly, in another study with people with working age dementia, little assistance
320 was available to help them keep working if they so wished [23]. In this study of 61 people, all but one
321 had to give up their jobs as they were unable to fulfil their work commitments. This was for a variety
322 of reasons including the inability to retain work-related insurance post-diagnosis, being laid off from
323 more informal work contracts, as well as voluntary decisions to leave work to spend more time with
324 family. Respondents in another study reported a sense of lack of agency, feeling conspired against and
325 often being dismissed without consultation [30]. In cases where a diagnosis had yet to be made, it was
326 common for an employee to lose their job due to poor performance before an opportunity for
327 workplace adjustments was considered [15]. Some employees with working age dementia reported

328 making self-directed adaptations to manage their condition [24]. These included developing new
329 strategies to perform tasks. These strategies were reported as helpful in work but also for non-work-
330 related activities and hobbies.

331

332 The authors of one study suggest that employees working in lower paid/manual jobs are more likely
333 to experience an 'all or nothing' approach from their employers, and face quicker dismissal. In
334 contrast, those working in higher paid/non-manual and professional jobs are more likely to have more
335 control over their daily tasks and more consideration may be given to retaining their unique
336 knowledge and remaining skills [4].

337

338

339 The third and final over-arching theme identified from the literature related to the provision of
340 information about working age dementia. Within this theme two sub-themes were identified: raising
341 awareness; facilitating informed choices.

342

343 The first sub-theme concerned the importance of accurate information about working age dementia in
344 raising awareness in the workplace. A lack of awareness of working age dementia in the general
345 population and in the workplace was commonly reported in the literature we reviewed [4,25]. This
346 was thought to result in lack of understanding and fear about how to interact with a person with
347 dementia [18]. People with working age dementia revealed, for example, that co-workers often did not
348 understand why they made mistakes [4].

349

350 Several articles noted the need to raise workplace awareness of possible signs and symptoms of
351 dementia, to provide information about dementia in staff newsletters and noticeboards areas, and to
352 provide training, perhaps by health and safety programmes [1,13,24,34,41,43]. Specific training for
353 co-workers was highlighted as a way of ensuring that those who work closely with a person with
354 dementia are patient, and that they listen and wait for their colleague with dementia to find the right

355 words [23]. The need to tackle stigma, encourage open dialogue and create an environment where
356 employees can talk about dementia was also highlighted [13].

357

358 Knowledge of employment law was also identified as a training need for health professionals working
359 in services for people with dementia [4]. Improved awareness of working age dementia among
360 general health professionals, particularly GPs, could encourage better multidisciplinary assessment
361 and quicker referral to specialists [23].

362

363 The second sub-theme identified the need for information to facilitate informed decision making by
364 people with working age dementia. The need for useful and timely information relating to working
365 age dementia was highlighted in many of the studies and reports. It was also noted that information,
366 support and services were difficult to access [1,18,43]. It was suggested that employers could be an
367 important focal point for dissemination. DEEP, for example, recommend that employers should
368 ensure that employees with working age dementia know to whom to turn for support, both inside and
369 outside the organisation [34].

370

371 Individuals diagnosed with working age dementia reported that they struggled to understand state
372 disability benefits and were unsure, for example, whether or not to remain in employment [43].
373 Financially-focused, informational support, including information about various state benefits, was
374 noted as essential for those working at the time of diagnosis [25,26,37,38,44]. Lack of suitable
375 information can make choosing between early retirement, redundancy or state benefits difficult and
376 inappropriate choices may cause additional financial hardship [1,4,28,30,35]. Also noted was that as
377 affected employees lose or leave their jobs, caregivers may also leave work in order to care for them,
378 resulting in further loss of income [24]. Employers should be encouraged to recognize dementia as a
379 reason for early retirement so as to maintain pension rights and other benefits [31,45].

380

381 DEEP emphasise the importance of employers supporting people to retire gradually by such measures
382 as: reducing hours and signposting to dementia friendly retirement clubs and activities [34]. As

383 working age dementia progresses, it is highly likely that there will come a time when an employee is
384 no longer able to fulfil a role within the organisation. At this stage, the literature makes clear that
385 there needs to be an open and honest discussion about available options, including advice about
386 pensions and benefits [13,20]. The UK's Alzheimer's Society [21] advises on the importance of
387 reaching agreement about a dignified exit package and strategy with each employee.

388

389 **Discussion**

390 This systematic review has identified and described current knowledge in relation to the management
391 of people who develop dementia whilst still in employment. The review identified 44 documents.
392 Their main themes concerned early presentation and identification in the workplace; reasonable
393 adjustments; and the provision of information both to raise awareness and allow employees with
394 working age dementia to make informed choices. The main limitation of the review is that there may
395 well be knowledge in working communities that has not been published. Since the topic of
396 employment and dementia sits across a wide span of health, social and occupational domains it is
397 possible that some omissions have been made. The aim of our review was to understand the
398 perspectives, experiences, and needs of employers rather than the work-related experience of people
399 with dementia; the latter has been the focus of previous research [4,5]. However, the literature
400 concerning how to manage people with working-age dementia remained heavily reliant on both the
401 perspectives and experiences of employees, and on best practice and advisory guides published by
402 charities and interest groups. There is very little primary research examining HR or OH practices and
403 interventions, or exploring the experiences of managers. Nevertheless, the experience of employees
404 with working-age dementia is clearly relevant and provides important insights into the management
405 practices they commonly experience, much of which they reported as negative.

406

407 The literature emphasised that early identification of dementia is important both for employer and
408 employee both to minimise problems arising at work and to enable employees to continue to work
409 after diagnosis should they so wish. Early identification can also help mitigate health and safety risks
410 and allow time for handover of knowledge and responsibilities. Early identification in the workplace

411 is challenging as employees conceal symptoms or self-manage them to reduce their impact at work.
412 Early symptoms can be varied and are manifested at work in a variety of ways: difficulty
413 remembering names, missing appointments, repetition during conversations, reduced numerical
414 ability, difficulty using logic, unexplained reductions in performance, increased agitation and
415 irritability, and symptoms of depression and anxiety. Employers are advised to interact sensitively
416 with employees suspected of having working-age dementia, expressing concern whilst supporting
417 them to access medical evaluations.

418

419 Although there is little evidence on the effectiveness of workplace adjustments for people with
420 working-age dementia, studies reporting employees' experiences highlight their desire to stay in work
421 and explain how employers can be supportive in this respect. A number of campaigning organisations
422 and charities provide guidelines on type of adjustments that can be put in place and the importance of
423 a collaborative approach to their implementation. However, as indicated above, the reported
424 experiences of people with working age dementia appear to be far from what is advised in such
425 guidance.

426

427 Information to raise awareness of the symptoms of working age dementia and to tackle stigma around
428 the condition was highlighted as a need, enabling employees to acknowledge and discuss the
429 problems they face managing people with dementia. Employers can help employees to talk about
430 their diagnosis and difficulties by creating an environment where dementia can be discussed, where
431 information about signs and symptoms is available, and where information about whom to turn to for
432 support and advice is provided [21,30].

433

434 It was noteworthy that the papers reviewed did not fully explore the issue of employee consent and
435 the ramifications of disclosure. While early disclosure may be desirable in order to facilitate
436 reasonable adjustments, without appropriate advice and knowledge of the legal requirement for
437 adjustments it may also, according to the literature, be associated with early exit from employment.

438

439 The majority of advice to employers on management of the condition in the workplace appears to
440 have been delivered by clinicians via the employee. The need for its practical application in
441 workplace settings and the role of the OH professional in achieving mutually satisfactory outcomes
442 was either under-recognised or not explored.

443

444 The UK workforce is ageing, such that by 2020, 1:3 British workers will be over 50 years of age
445 [46,47]. It is likely that employers will need to retain older workers to access scarce skills. At the
446 same time, the incidence of dementia also increases with age, doubling every 5 years from the age of
447 65 to 90 [48]. Many with an early diagnosis will be capable of sustained, productive employment with
448 reasonable adjustments. The literature does not examine the business case for managing dementia to
449 retain critical skills.

450

451 Neither did the literature we reviewed explore whether employers should include cognitive testing as
452 part of employee review procedures, or whether employers and OH professionals should take a more
453 proactive approach towards detecting and diagnosing cognitive impairment amongst employees. This
454 will be the subject for further research from our group.

455

456 The 'Dementia Friends' initiative run by the Alzheimer's Society in the UK aims to make positive
457 changes to the way employers and businesses respond to dementia in the community [28].
458 Information sessions for businesses help all their employees learn about dementia and the steps they
459 can take to help. Many organisations have committed to helping their employees understand more
460 about dementia through this initiative.

461

462 In conclusion, there is an acknowledged lack of awareness among employers about working age
463 dementia, and how it may be better managed for the benefit of employees and employers. Guidance
464 for employers is increasingly becoming available although it rarely refers to the evidence base. There
465 is a need for studies that explore the effectiveness of guidance for both employees and employers, as
466 well as the value of awareness raising and training initiatives. Examples of good practice where

467 employees with dementia have been able to remain in the workforce for as long as is practicable and
468 who have left the workforce with dignity and support, would be helpful.

469

470 **Key points:**

- 471 • Early identification of dementia is important both for employer and employee to minimise
472 problems arising at work and enable employees to continue to work after diagnosis should they
473 so wish
- 474 • People with working age dementia often have a strong desire to stay in work for as long as
475 possible, and this can be facilitated by reasonable adjustments that are regularly reviewed.
- 476 • Employers can help employees to talk about their diagnosis and difficulties by creating an
477 environment where dementia can be discussed, and where information is available about signs
478 and symptoms, and whom to turn to for support and advice

479

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485

486 **Competing interests**

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488

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491

492

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607 Table 1. Types of Article

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Type of Article	Country of Publication					Total
	UK	USA	Austalia/ New Zealand	Other	Joint	
Journal article	10	5	3	3	1	22
Professional/magazine article	4	2	0	0	0	6
Brochure/Guidance	4	1	0	0	0	5
Policy report/statement	4	2	0	0	0	6
Webpage	0	0	2	0	0	2
Press release	2	0	0	0	0	2
Thesis	1	0	0	0	0	1
	26	10	5	3	1	44

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612 Table 2. Critical Appraisals Skills Programme Qualitative Research Checklist Scores for Journal

613 Articles

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Author	Year	Score
Harris & Keady	2009	10
Mitchell	2012	10
Pipon-Young et al.	2011	10
Batsch & Miller	2009	9
Chaplin and Davidson	2016	9
Clemerson et al.	2014	9
Roach & Drummond	2014	9
Van Vliet et al.	2011	9
Bakker et al.	2010	8
Haase	2005	8
Roach et al	2008	8
Wahab & Ikebucu	2014	8
Chaston	2011	7
Keady & Nolan	1994	6
Thompson	2011	5
Werner et al.	2009	5
Dibia et al.	2015	4
Tindall & Manthorpe	1997	2
Chaston	2010	0
Baker	2008	N/A
Bentham & La Fontaine	2008	N/A
Dodson	1985	N/A

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618 Table 3. Over-arching themes and sub-themes

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Themes	Sub-themes
Early presentation and identification in the workplace	Hiding difficulties Early symptoms From symptoms to diagnosis Interactions with employees
Reasonable adjustments	The desire to stay in work Typical adjustments Process of making adjustments Reported experiences of reasonable adjustments
Provision of information	Raising awareness Facilitating informed choice

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622 Table 4. Reasonable adjustments described in the grey literature

REASONABLE ADJUSTMENTS	Alzheimer's Society (2010; 2016)	Job Access website	Alzheimer's Australia
changing work schedules, or reducing hours	xx	x	
arranging meetings for times when employees are likely to be at their best	x		
simplifying routines, and allocating tasks separately instead of all at once	x		
reducing noise and distraction	x		
using technology (e.g. computerised diaries) to function as reminders of meetings and deadlines	x		
moving to a less senior role and accepting a lower wage and less responsibility	x		
having one or two colleagues as supporters		x	x
assistance with planning for the future e.g. deciding when the time is right to leave work		x	
identify who else in the workplace needs to know about the diagnosis. (clients as well as co-workers)			x

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628 Table 5. Good practice in the process of making adjustments at work

GOOD PRACTICE FOR EMPLOYERS	Alzheimer's Society (2014)	DEEP (2013)
Encourage an open and honest dialogue of options to help the person stay in work	x	x
Seek further advice to identify ways to make reasonable adjustment, e.g. OH services, local memory services	x	x
Demonstrate they have made reasonable adjustments to enable people who develop dementia to continue to work, and reassure employees that the organisation will support them where possible		x
Be flexible and use the skills of the individuals involved, adjusting certain parts of the job where necessary		x
Make sure the person knows that their skills and experience are still valued		x
Carry out risk assessments and review the situation frequently with the employee		x
Acknowledge that supporting people may take time and resources – people may need practical and emotional support		
Be honest about adjustments that can reasonably be made, and provide information and guidance about finishing work to people with dementia and carers who are unable, or no longer wish to, continue working	x	x

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631 Figure 1. Flow chart for the identification of articles

