

Bangor University

PROFESSIONAL DOCTORATES

The psychological impact of having a parent with a progressive neurodegenerative condition

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Appendix 1: Quality Checklists for studies included within the integrative review

Quality Checklist framework for quantitative papers

	Decruyenaere et al. (1999)	Folstein et al. (1983)	Vamos et al. (2007)	Van der Meer et al. (2006)	Van der Meer et al. (2012)	Williams et al (2013)
Abstract summarises key results?	√√	√	√	√	√√	√
Rationale for research clearly outlined?	√√	√	√	√√	√√	√
Clear research aims?	√√	√	√	√√	√	√
Ethical issues identified and addressed?	-		√	-	√	-
Justified use of methodology employed?	√	√	√	√√	√√	√
Clear study design?	√	-	√	√√	√	√
Clearly stated hypotheses?	√√	√√	-	√√	√	-
Population identified?	√	√	√	√	√	√
Sample described in detail?	√	√	√	√√	√√	√
Valid and reliable data collection?	√√	-	√√	√√	√√	√
Valid and reliable data analysis?	√√	√	√√	√√	√√	√
Clear statement of findings?	√√	√	√	√√	√√	√
Comprehensive discussion?	√	√	√√	√√	√√	√√
Generalizability of results?	√√	√	√	√	√√	√
Comprehensive conclusion?	-	√	-	√	√	-

Quality checklist for qualitative studies

	Duncan et al. (2007)	Forrest-Keenan et al. (2007)	Forrest-Keenan et al. (2009)	Korer & Fitzimmons (1987)	Sparbel et al. (2008)	Williams et al. (2009)
Abstract summarises key results?	√	√ √	√ √	√	√	√
Rationale for research clearly outlined?	√ √	√ √	√ √	√	√ √	√ √
Clear research aims?	√ √	√ √	√ √	√	√	√
Ethical issues identified and addressed?	√	√	√ √	-	√	√
Justified use of methodology employed?	√	√	√	√	√	√
Philosophical background and study design identified?	-	-	-	-	-	-
Major concepts identified?	-	-	-	-	-	-
Context of study outlined?	√	√	√ √	√	√	√
Sample described in detail?	√	√	√	√	√	√
Auditable data collection?	√	√	√ √	-	√ √	√ √
Credible and confirmable data analysis?	√	√	√	√	√	√ √
Clear statement of findings?	√ √	√ √	√ √	√	√ √	√ √
Comprehensive discussion?	√ √	√ √	√ √	√	√ √	√ √
Transferability of results?	√ √	√ √	√ √	√	√ √	√ √
Comprehensive conclusion?	√	√ √	√	-	√	√ √

Appendix 2: Summary of literature review papers

Table 1: Quantitative studies included in the review

STUDY	Participants	Design and Method	Relevant Key Findings	Potential Limitations
Decruyenaere et al. (1999) Netherlands	N=69 (40 non-carriers, 29 carriers) mean age 31 years Recruited via a genetics clinic	Cohort study, standardised questionnaires Anxiety: STAI, Depression: BDI, Ego strength: MMPI, administered one year prior to genetic testing. Clinical interview.	Significant, but low, correlations between age of parental disease onset and psychological functioning. Those younger than 5 years of age at parental HD onset showed the highest levels of depression and anxiety and lowest levels of ego strength Gender of parent did not impact on psychological functioning pre or post-test.	Reliance on retrospective reporting about childhood experiences
Folstein et al. (1983) USA	N=112 offspring from 34 HD families mean age 26.7 years (range 5-47), 11 had HD confirmed and 15 suspected before age of 30. Recruited from clinic database	Participants interviewed using structured diagnostic interview (NIMH DIS), 67 interviewed in person, 45 interviewed either by telephone or information gathered via relative.	Conduct disorder and anti-social personality (ASP) related to a combination of poor parenting, disorganisation and non-HD parent factors. Conduct disorder / ASP = 25% (28/112) of participants, and significantly associated with growing up in a disorganised family and early onset of parental HD. ASP was also related to a psychiatric diagnosis in the non-HD affected parent, but not the HD parent, unless the family was classified as disorganised. Major Affective Disorder = 18% (20/112) onset in late adolescence/early adulthood was related to presence of it in HD parent.	Reliance on informant perspective for some participants. Different criteria used to define major affective disorder depending upon whether or not the participant was interviewed in person.
Vamos et al. (2007) Australia	40 adult offspring of HD parents Mean age 31.08 years (range 19-40). 50% female Recruited from a genetic unit and local	Postal Questionnaire Measures: Psychological well-being = K10 Parenting style = MOPS Family functioning = FRI.	Average levels of psychological well-being, but significant parental dysfunction was observed. Irrespective of HD status fathers and mothers scored highest on over-control parenting style. Paternal dysfunction was significantly lower than depressed reference group. Maternal dysfunction scores were similar to depressed reference group. Family functioning scores were all in the dysfunctional range (cohesiveness 2.5, expressiveness 1.7, conflict 2.10)	Low response rate raises possibility that those in most need were the non-respondents. Lack of demographics. Small N

	newspaper adverts. (50% response rate)	10 item non standardised questionnaire about the impact of HD.	total – 6.17). These scores were unrelated to parental gender or participants 80% of participants expressed difficulty growing up in a HD family, but 65% felt good about their family. 72.5% felt that they could cope. 40% reported that HD had split family apart. HD was endorsed as the biggest issue facing the family in 27.5% of cases	
Van der Meer et al. (2006) Netherlands	N= 32 18-58 year olds mean age 29.94 years 14 m 18f Participants recruited from genetic clinic and HD organisation. Control/reference group – n=870 adults for AAI classifications and n=728 for unresolved	AAI interview and biographical data	Only 38.7% HD sample securely attached compared to 59.2% of the reference group. 45.2% of HD group had a preoccupied attachment style compared to 17.6% of the reference group. Significantly higher levels of unresolved/disorganised attachment representations were reported in the HD group (53.1%) compared to the reference group (18.4%) Those with insecure attachments were most likely to have been raised in a family where HD was younger onset, and they learned about HD and experienced HD-related death and trauma at a younger age. Unresolved/disorganised attachment was also related to lower age of HD diagnosis.	Potential sample bias – recruited from a HD group and genetic clinic findings may not be reflective of the general HD population. Reliant on subjective recall of childhood experiences for some this would have been 40 years ago
Van der Meer et al. (2012) Netherlands	N= 74 HD mean age 35.4 (range 18-65) 82 BRCA mean age 40 (range 18-65) 101 partner controls mean 38.8 (18-64) Recruited from genetics clinics, controls were partners of	Questionnaire demographics, NLES (19 item) focus on events before the age of 16	53% HD offspring and 45% BRCA had experienced adversity growing up. HD had significantly more (adverse childhood experiences (ACEs) than controls and BRCA participants. The number of ACEs correlated with age of onset of HD. HD offspring experienced significantly higher levels of parental dysfunction to controls and BRCA sample. HD parents significantly more likely to have psychological problems (>20%), and for there to have been domestic violence in the household, also more likely to have attempted suicide than BRCA parents. No significant difference in level of abuse.	Retrospective reporting, large age range. Self-selecting bias of being clinic attenders may lead to under-reporting. Control group primarily male. Limited information about nature of the ACEs.

	those approached			
Williams et al. (2013) USA	N=44 14-30 year olds recruited via HD database 68% female	Postal survey 75 item coping questionnaire (Alpha co-efficient .92)	Coping strategies used by adolescents reflected 4 categories related to use and helpfulness (i) low-use-high helpfulness - talking to those working in HD, accessing support groups and attending conferences, having parent in the house if hospitalised, limited alcohol, stimulants (ii) low use-low helpfulness - seeing a counsellor, talking to friends, social services, using drugs, alcohol in order to cope (iii)high use – high helpfulness -self-research, spending quality time with HD parent, activities away from HD situation, communicating with HD parent, spending time with friends (iv) high use-low helpfulness - hiding emotions from others) Gender differences: females more like to use a variety of coping strategies both emotion and problem-focused	Potential bias in coping strategies reported due to sample selection due to parental gate keeping. Wide age range and retrospective reporting may also influence results.

AAI =Adult Attachment Interview (Main, Kaplan & Cassidy,1985); BDI = Beck Depression Inventory (Beck, 1961); FRI = Family Relationship Index (Hoge, Andrews, Faulkner, & Robinson, 1989); K10 (Andrew & Slade, 2001); MMPI = Minnesota Multiphasic Personality Inventory(Hathaway & McKinley, 1940); MOPS = Measure of Parental Style (Parker et al., 1997); NLES = Negative Life Events Scale(Cohen, Tyrell & Smith, 1993); NIMH DIS = Diagnostic Interview Schedule (Hendricks et al., 1983)) STAI = State Trait Anxiety Scale (Spielberger 1983);.

Table 2: Qualitative studies included in the review

STUDY	Design and Method	Participants	Key Findings	Potential Limitations
Duncan et al. (2007) Australia	Semi-structured interviews Thematic analysis	N=8 (4 males and 4 females) aged between 15-24 years of age. 2 gene positive 6 gene negative. Recruited from genetics service	Prior to genetic testing young people were in fear of being a carrier, and the impact it would have on their family. Over half of participants had engaged in substance misuse in order to manage feelings of uncertainty over their HD risk. After genetic testing young people reported how, irrespective of the result, it had a positive impact reducing anxiety, leading to positive lifestyles and coping strategies	Focus of study was not specifically on impact of genetic testing on family relationships. Small number of participants Potential recall bias
Forest Keenan et al. (2007) Scotland, UK	Semi-structured interviews Thematic analysis	N=33 young people aged between 9-25 mean age 20.5 years. 21 females 12 males. Recruited from genetics clinics and Scottish HD Association 26 at 50% risk 5 no mutation	Under 18s carried out adult care-giving duties, they expressed difficulties in meeting their parent's needs, and having their own needs as an adolescent met. Over 18s expressed a need for practical and emotional support, they struggled to combine study/work/their own families with a care-giving role. Most used adaptive coping strategies. Two thirds of the sample had sought psychological support. Knowing one's own HD status was associated with adaptive coping. Older age at discovering HD risk was associated with more HD related concerns which impacted on psychological well-being and relationships.	Potential under-reporting of difficulties. Reliance on parental consent for younger participants may have excluded those in most need. Some reports were retrospective about experiences
Forest-Keenan et al. (2009) Scotland, UK	Semi-structured interviews Thematic analysis	Same as Forest-Keenan 2007	Most young people found out about HD from a female relative. Almost half had always known about HD, a quarter were told gradually, after becoming aware of the family illness, and some young people felt that parents kept it a "secret" until they felt they were old enough to understand. This caused friction in some families, but in some cases young people could understand their parents' reasoning.	See Forest-Keenan et al 2007
Korer & Fitzsimmons (1987) UK	Semi-structured interviews Content analysis	N=50 13-25 year olds 50% risk n=29 25% risk n=21	Two thirds of participants had developed coping strategies to manage the uncertainty they faced, but a number struggled to manage parental fear. Participants at 25% risk were able to put HD risk to one side, those at 50% risk couldn't and a number were hyper-vigilant to HD symptoms and rumination.	Some retrospective reporting. Potential sample bias due to parental gate-keeping re providing consent particularly in those at 25% risk of HD.

		Recruited from genetics clinic and GP registers.	Of those at 50% risk, 55% were planning to have a family compared to 86% at 25% risk.	Study predates the availability of pre-symptomatic testing
Sparbel et al. (2008) USA/CANADA	Focus groups x 6 (2-8 participants) Content analysis	N=32 Age range 14-18 years. Mean age 15.9 years. Female: Male ratio 3:1 Recruited via HD centres 84% at risk of HD	Young people experienced (i) Depression and helplessness as relatives' health deteriorated, and distress at emotional unpredictability of HD. This led to a fear of future planning, having own family (ii) Isolation from both family and peers, concerns that own risk was not being understood by non-affected parent. Lack of communication with both affected and non-affected parent. Sense of not being the same as peers (iii) conflict, stress and estrangement within the family and wider family network. (iv) taking on adult care-giving responsibilities, management of stress in non-affected parent. Self-reproach, guilt of wanting own independence.	Relied on parental consent. Gate keeping by parent may have biased participants. Potential for lack of disclosure in focus groups which may have led to downplaying of concerns
Williams et al. (2009) USA/CANADA	Same as Sparbel et al. (2008)	Same as Sparbel et al. (2008)	Adolescents growing up in HD families have similar and unique care-giving experiences to adult caregivers. Shared experiences with adult caregivers were: (i) taking on both practical and emotional care-giving tasks and managing emotional and behavioural changes in their relative; (ii) subjective burden, emotional distress depression, isolation and loneliness and financial pressures caused by the care-giving role. Unique care-giving experiences were: (i) Care-giving in the knowledge of own risk of developing HD; daily reminders of own risk, and managing fear of developing HD and how it may impact on own life plans (e.g. relationships) in context of providing care. (ii) Having to make important decisions regarding care whilst too young to have legal authority and reliance upon help and support from adults to achieve this	See Sparbel et al. (2008)

Appendix 3: Participant information sheets, letters of invite and consent form

**RHAGLEN SEICOLEG CLINIGOL GOGLEDD CYMRU
NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME**

June 2013

Dear prospective participant

RE: The experience of having a parent diagnosed with dementia before the age of 65.

You have been identified, either by a family member or a member of health care staff within Betsi Cadwaladr University Health Board, as someone who has a parent living with a diagnosis of dementia that was diagnosed before they were 65 years of age.

I am writing to ask if you would be willing to consider taking part in a research study looking at the experiences of people who have a parent with such a diagnosis. There is currently little research in this area and we feel that it is important to gain a greater understanding of how such a diagnosis impacts on patient's sons or daughters.

This study forms part of my doctoral thesis in clinical psychology which is supervised by Professor Bob Woods (Professor of Clinical Psychology and Co-Director Dementia Services Development Centre, Wales). The study involves taking part in a one-off interview lasting between 45 minutes to an hour where you would be able to discuss your experiences. Whether you choose to participate in this study or not will not affect any treatment either your parent or yourself receives in any way. All information provided will be made anonymous and treated in the strictest of confidence in line with ethical and legal practice.

If you are interested in taking part please read the enclosed information sheet carefully and talk it over with family and friends before coming to a decision. All participants must be over 18 years of age. You should not feel under any obligation to take part in this study as a result of receiving this information pack. If you do have any questions please do not hesitate to contact me, Dr Helen Aslett, Principal Investigator either by telephone on 07546309221 or by email at ppcb5@bangor.ac.uk. Alternatively please contact my project supervisor Professor Bob Woods (Professor of Clinical Psychology and Co-Director Dementia Services Development Centre, Wales) either by telephone on 01248 382463 or by email at b.woods@bangor.ac.uk

Thank you for your time.

Yours sincerely

Dr Helen J Aslett (Principal Investigator) – On behalf of the research team.

**RHAGLEN SEICOLEG GLINIGOL GOGLEDD CYMRU
NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME**

Mehfin 2013

Annwyl ddarpar gyfranogwr,

PARTHED: Y profiad o fod â rhiant sydd wedi cael diagnosis o ddementia cyn 65 oed.

Rydych wedi cael eich enwi, naill ai gan berthynas i chi neu gan weithiwr gofal iechyd ym Mwrdd Iechyd Prifysgol Betsi Cadwaladr, fel rhywun dros 18 oed sydd â rhiant sydd wedi cael diagnosis o ddementia cyn 65 oed. Ysgrifennaf atoch i ofyn i chi a fydddech yn fodlon ystyried cymryd rhan mewn astudiaeth ymchwil sy'n edrych ar brofiad pobl sydd â rhiant sydd wedi cael diagnosis o'r fath. Ar hyn o bryd nid oes llawer o ymchwil wedi ei wneud yn y maes hwn ac rydym yn credu ei fod yn bwysig deall mwy am sut mae diagnosis o'r fath yn effeithio ar blant cleifion.

Mae'r astudiaeth hon yn rhan o'm doethuriaeth mewn seicoleg glinigol a oruchwylir gan yr Athro Bob Woods (Athro Seicoleg Glinigol a Chyd-gyfarwyddwr Canolfan Datblygu Gwasanaethau Dementia Cymru). Bydd bod yn rhan o'r astudiaeth yn golygu y byddwch yn cymryd rhan mewn cyfweiliad unigol fydd yn para rhwng tri chwarter awr ac awr i drafod eich profiad. Ni fydd eich penderfyniad i gymryd rhan neu beidio yn yr astudiaeth hon yn effeithio mewn unrhyw ffordd ar driniaeth eich rhiant na'ch triniaeth chithau. Bydd yr holl fanylion personol amdanoch yn cael eu tynnu o'r wybodaeth y byddwch yn ei rhoi a chedwir yr holl wybodaeth yn gwbl gyfrinachol yn unol ag arferion moesegol a chyfreithiol.

Os oes gennych ddiddordeb cymryd rhan, darllenwch y daflen wybodaeth sy'n amgaeedig yn ofalus a thrafodwch y mater gyda'ch teulu a'ch ffrindiau cyn penderfynu. Mae'n rhaid i gyfranogwyr fod dros 18 oed. Ni ddylech deimlo unrhyw reidrwydd i gymryd rhan yn yr astudiaeth hon oherwydd y gwahoddiad hwn. Os bydd gennych unrhyw gwestiynau, cysylltwch â mi, Dr Helen Aslett, y prif ymchwilydd, naill ai trwy ffonio 07546309221 neu anfon e-bost i pspcb5@bangor.ac.uk. Neu cysylltwch â goruchwyliwr fy mhroject, yr Athro Bob Woods (Athro Seicoleg Glinigol a Chyd-gyfarwyddwr Canolfan Datblygu Gwasanaethau Dementia Cymru) naill ai trwy ffonio 01248 382463 neu trwy anfon e-bost i b.woods@bangor.ac.uk

Diolch i chi am roi o'ch amser.

Yn gywir

Dr Helen J Aslett (prif ymchwilydd) – ar ran y tîm ymchwil

**RHAGLEN SEICOLEG CLINIGOL GOGLEDD CYMRU
NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME**

PARTICIPANT INFORMATION SHEET

- 1. STUDY TITLE:** The experience of having a parent diagnosed with dementia before the age of 65.
- 2. INVITATION:** We would like to invite you to take part in our research study which is trying to develop our understanding of the experiences of individuals who have a parent diagnosed with dementia before the age of sixty-five. This would involve taking part in an individual interview lasting approximately 45 minutes to one hour where you would discuss your experiences.

Before you decide whether or not to take part in this study it is important that you understand why it is being carried out and what it will involve. Please take time to read the following information sheet carefully and discuss it with friends or relatives if you wish. You should not feel under any obligation to take part in this study because you have been given this invitation. If there is anything that is not clear to you, or if you have any questions, please contact Dr Helen Aslett, the principal investigator on this project whose contact details are at the end of this sheet.

Thank you for reading this.

- 3. What is the purpose of this study?** In this study we are seeking to gain a better understanding of the experiences of individuals who have a parent living with a dementia that was diagnosed before the age of 65. There is currently little research in this area and this is something that we hope to address. Whilst the purpose of this research is primarily educational it is hoped that the findings will be published to a wider audience. Recruitment to this study is across clinics within the Betsi Cadwaladr University Health Board.
- 4. Why have I been invited?** You have received this information pack as you have been identified by a health care worker, at one of the clinics involved in the study, as someone who is over 18 years of age who has a parent who was diagnosed with dementia before the age of 65. We are contacting you to ask whether you would be willing to participate in an individual interview so that we can learn more about your experiences.

- 5. Do I have to take part?** No, it is entirely up to you to decide whether or not to take part. If, having read the information sheet, you do not wish to take part you may dispose of this information pack immediately. Whether you choose to take part in the study or not, will not affect any treatment offered to your parent or support offered to you in any way. Taking part in the study will however, help us to develop a greater understanding of the experiences of individuals whose parents have a dementia diagnosis before the age of 65. If you agree to take part in the study we would ask you to sign a consent form, but you are free to withdraw from the study at any time without giving a reason. Again this would not affect the care you or your parent receives.
- 6. What will happen to me if I take part?** If you decide to take part, please contact Dr Helen Aslett either by email at pspcb5@bangor.ac.uk, telephoning or by sending a text message to 07546309221. If replying by email please make sure you include a telephone number. Dr Helen Aslett will then telephone you to arrange a time to come and talk to you about your experiences. The interview can either take place at the clinic where your parent receives medical support, at Bangor University or at your home, whichever is most convenient for you.

Before the interview you will be asked to sign a consent form to say that you understand the purpose of the study, your right to withdraw from it and any time and agreeing to the interview being audio recorded. The interview will last approximately 45 minutes to one hour, in which you will be asked to talk about your experiences of having a parent with a dementia diagnosis. The interview will be audio recorded, but your identity will remain confidential at all times. Please note that participants must be over 18 years of age. After the interview you will be offered a £10 gift voucher as a token for your participation in this study.

- 7. Are there any disadvantages, risks or benefits from taking part in this study?** We know of no disadvantages or risks associated with taking part. There may be no direct or immediate benefits to yourself from taking part, and the current study is for research purposes only, but there may be potential long-term benefits to taking part. Your contribution may help us to gain a greater understanding of issues facing individuals whose parents have a dementia diagnosis prior to the age of 65.

The interviews may touch on issues that give rise to concerns regarding your mood and well-being, particularly if you have never spoken to anyone about your experiences until now. If such issues arise during the interview we will

discuss possible sources of help and referral. You might also wish to contact one of the following support lines:
Alzheimers Society 0845 3000336 or Admiral Nursing Direct 0845 257 9406
Alternatively you might like to contact the clinical nurse specialist (CNS) at the clinic where your parent attends.

Dr Helen Aslett will also telephone you within 48 hours of being interviewed to check whether the interviews have prompted any issues for you and to check whether you are still happy for your interview to be included in the study.

- 8. Will my taking part in this study be kept confidential?** Yes. We will follow ethical and legal practice (Data Protection Act, 1988). All information about you will be handled in confidence. Your participation in the study will remain completely confidential. Only members of the research team (see Q9) will see the transcript of the interview. The audio recording of your interview will also be destroyed immediately after transcription by Dr Helen Aslett. The transcript will be made anonymous, password protected and stored on a password encrypted pen drive.

Your interview transcript will be assigned a unique code so that your name is not on any information you have provided and your consent form will be stored separately to your transcript so that it cannot be identified. The unique code will enable us to match your details to your transcript should you wish to withdraw from the study at a later date. All data will be destroyed five years after the completion of the research. Any information used in reports or papers about the research will be anonymised including direct quotations from the interviews.

- 9. Who is organizing and funding this study?** The research is being carried out by Dr Helen Aslett a trainee clinical psychologist at Bangor University, Wales under the supervision of Professor Bob Woods (Professor of Clinical Psychology and Co-Director Dementia Services Development Centre, Wales), Dr Joanne Kelly-Rhind (Clinical Psychologist) and Dr Jaci Huws (Research methods supervisor). This study is not being funded by an external body.
- 10. Who has reviewed the ethics of this study?** The study has been reviewed and approved by the Bangor University School of Psychology Research Ethics and Governance Committee and the North Wales Research Ethics and R&D Committees (West).
- 11. Who can I contact for further information?** If you have any questions about this project, or if you want to talk to somebody before taking part, please contact

Dr Helen Aslett telephone on 07546309221 between 9am-5pm, or email pspcb5@bangor.ac.uk or write to her at the North Wales Clinical Psychology Programme, School of Psychology, Bangor University, Bangor, Gwynedd. LL57 2DG. Alternatively please contact Professor Bob Woods on 01248 382463 or b.woods@bangor.ac.uk

- 12. Complaints:** If at any time you have any complaint about the way that the research has been conducted, please contact Hefin Francis, School Manager, School of Psychology, Bangor University, Bangor. LL57 2AS. Telephone 01248 388339.

Thank you for taking the time to read this information sheet.

**RHAGLEN SEICOLEG GLINIGOL GOGLEDD CYMRU
NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME**

TAFLEN WYBODAETH I GYFRANOGWYR

- 1. TEITL YR ASTUDIAETH:** Y profiad o fod â rhiant sydd wedi cael diagnosis o ddementia cyn 65 oed.
- 2. GWAHODDIAD:** Hoffem eich gwahodd i gymryd rhan yn ein hastudiaeth ymchwil sy'n ceisio cynyddu ein dealltwriaeth o brofiadau pobl sydd â rhiant sydd wedi cael diagnosis o ddementia cyn 65 oed. Bydd hyn yn golygu cymryd rhan mewn cyfweiliad unigol fydd yn para rhwng tri chwarter awr ac awr i drafod eich profiad.

Cyn ichi benderfynu a hoffech gymryd rhan, mae'n bwysig eich bod yn deall pam rydym yn gwneud yr astudiaeth a beth fydd yn digwydd. Cymerwch amser i ddarllen y daflen wybodaeth isod yn ofalus a'i thrafod â ffrindiau neu berthnasau os dymunwch. Ni ddylech deimlo unrhyw reidrwydd i gymryd rhan yn yr astudiaeth hon oherwydd y gwahoddiad hwn. Os ydych yn ansicr ynglŷn â rhywbeth, neu os oes gennych unrhyw gwestiynau, cysylltwch â Dr Helen Aslett, prif ymchwilydd yr astudiaeth hon. Mae ei manylion cyswllt ar waelod y daflen hon.

Diolch i chi am ddarllen hwn.

- 3. Beth yw diben yr astudiaeth hon?** Yn yr astudiaeth ymchwil hon rydym yn ceisio cynyddu ein dealltwriaeth o brofiadau pobl sydd â rhiant sy'n byw gyda dementia ac a gafodd y diagnosis o ddementia cyn 65 oed. Ar hyn o bryd nid oes llawer o ymchwil wedi ei wneud yn y maes hwn ac mae hyn yn rhywbeth yr ydym yn gobeithio ei newid. Er mai at ddibenion addysgol y gwneir yr astudiaeth hon yn bennaf, gobeithir y caiff y canlyniadau eu cyhoeddi ac y byddant ar gael i gynulleidfa fwy. Caiff cyfranogwyr eu recriwtio i'r astudiaeth hon trwy glinigau Bwrdd Iechyd Prifysgol Betsi Cadwaladr.
- 4. Pam wyf wedi cael gwahoddiad?** Anfonwyd y pecyn gwybodaeth hwn atoch oherwydd bod gweithiwr gofal iechyd yn un ô'r clinigau sy'n rhan o'r astudiaeth hon wedi eich enwi fel rhywun dros 18 oed sydd â rhiant sydd wedi cael diagnosis o ddementia cyn 65 oed. Rydym yn cysylltu â chi i ofyn a fyddech yn fodlon cymryd rhan mewn cyfweiliad unigol er mwyn inni ddysgu mwy am eich profiad.

5. A oes rhaid imi gymryd rhan? Nac oes, chi sydd i benderfynu a ydych am gymryd rhan yn yr astudiaeth. Os na fyddwch yn dymuno cymryd rhan ar ôl darllen y daflen wybodaeth hon, gallwch daflu'r pecyn gwybodaeth hwn ar unwaith. Ni fydd eich penderfyniad i gymryd rhan neu beidio yn yr astudiaeth hon yn effeithio mewn unrhyw ffordd ar y driniaeth a gynigir i'ch rhiant nac ar y gefnogaeth a gynigir i chi. Ond os cymerwch ran yn yr astudiaeth, bydd hynny'n gymorth i ni gynyddu ein dealltwriaeth o'r profiad o fod â rhiant sydd wedi cael diagnosis o ddementia cyn 65 oed. Os byddwch yn cytuno i gymryd rhan yn yr astudiaeth, byddwn yn gofyn i chi lofnodi ffurflen gydsynio, ond gallwch dynnu'n ôl o'r astudiaeth ar unrhyw adeg a heb roi rheswm. Ni fyddai hynny'n effeithio ar safon y gofal yr ydych chi neu eich rhiant yn ei gael.

6. Beth fydd yn digwydd i mi os byddaf yn cymryd rhan? Os penderfynwch gymryd ran, cysylltwch â Dr Helen Aslett naill ai trwy anfon e-bost i pspcb5@bangor.ac.uk neu trwy ffonio neu anfon neges destun i 07546309221. Os byddwch yn anfon e-bost, cofiwch gynnwys rhif ffôn yn eich neges. Wedyn bydd Dr Helen Aslett yn eich ffonio i drefnu amser i ddod i siarad â chi am eich profiad. Gellir cynnal y cyfweiliad yn y clinig lle mae eich rhiant yn cael cefnogaeth feddygol, ym Mhrifysgol Bangor neu yn eich cartref, pa bynnag un sydd fwyaf cyfleus i chi.

Cyn y cyfweiliad gofynnir i chi lofnodi ffurflen gydsynio i ddweud eich bod yn deall diben yr astudiaeth, eich hawl i dynnu'n ôl o'r astudiaeth ar unrhyw adeg a'ch bod yn cytuno i'r cyfweiliad gael ei recordio ar dâp sain. Bydd y cyfweiliad yn para rhwng tri chwarter awr ac awr ac yn ystod y cyfweiliad gofynnir i chi drafod eich profiad o fod â rhiant sydd wedi cael diagnosis o ddementia. Caiff y cyfweiliad ei recordio ar dâp sain, ond caiff eich manylion personol eu cadw'n gyfrinachol trwy'r amser. Mae'n rhaid i gyfranogwyr fod dros 18 oed. Ar ôl y cyfweiliad, ceuwch daleb gwerth £10 i ddiolch i chi am gymryd rhan yn yr astudiaeth hon.

7. A oes unrhyw anfanteision, risgiau neu fanteision o gymryd rhan yn yr astudiaeth hon? Nid ydym yn gwybod am unrhyw anfanteision na risgiau sy'n gysylltiedig â chymryd rhan. Ac er na fydd unrhyw fanteision uniongyrchol i chi efallai ac y gwneir yr astudiaeth at ddibenion ymchwil yn unig, efallai y bydd manteision tymor hir i chi o gymryd rhan. Ond mae'n bosib y bydd eich cyfraniad yn gymorth i ni ddeall y problemau sy'n wynebu pobl sydd â rhiant sydd wedi cael diagnosis o ddementia cyn 65 oed.

Mae'n bosib y bydd y cyfweiliadau'n cyffwrdd â materion fydd yn arwain at bryder am eich hwyliau a'ch lles, yn enwedig os na fyddwch wedi siarad am eich

profiadau erioed o'r blaen. Os bydd materion o'r fath yn codi yn ystod y cyfweiliad, byddwn yn sôn wrthyh am ffynonellau cymorth posib ac yn eich cyfeirio atynt. Efallai y byddwch eisiau cysylltu ag un o'r llinellau cymorth canlynol hefyd:

Alzheimers Society 0845 3000336 neu Admiral Nursing Direct 0845 257 9406
Gallech hefyd gysylltu â'r nyrs glinigol arbenigol yn y clinig y mae eich rhiant yn mynd iddo.

Bydd Dr Helen Aslett hefyd yn eich ffonio cyn pen 48 awr ar ôl y cyfweiliad i sicrhau nad yw'r cyfweiliad wedi gwneud ichi ddechrau meddwl am bethau sy'n peri pryder i chi ac i holi a ydych yn dal yn fodlon i'ch cyfweiliad gael ei gynnwys yn yr astudiaeth.

- 8. A fydd y ffaith fy mod yn cymryd rhan yn yr astudiaeth hon yn cael ei chadw'n gyfrinachol?** Bydd. Byddwn yn dilyn arferion moesegol a chyfreithiol (Deddf Diogelu Data, 1988). Caiff yr holl wybodaeth amdanoch chi ei thrin yn gyfrinachol. Bydd eich cyfraniad at yr astudiaeth yn aros yn gwbl gyfrinachol. Dim ond aelodau'r tîm ymchwil (gweler cwestiwn 9) fydd yn cael gweld y trawsgrifiad o'r cyfweiliad. Caiff y tâp sain o'ch cyfweiliad ei ddinistrio yn syth ar ôl i Dr Helen Aslett ei drawsgrifio. Caiff eich manylion personol eu tynnu o'r data fel na fydd modd eich adnabod, caiff y data ei gadw ar gof bach wedi ei amgryptio gyda chyfrinair.

Rhoddir cod unigryw ar eich trawsgrifiad fel na chysylltir eich enw â'r wybodaeth ynddo a chaiff eich ffurflen gydsynio ei chadw ar wahân fel na fydd modd ei chysylltu â'r trawsgrifiad. Bydd y cod unigryw yn caniatáu i ni baru eich manylion gyda'ch trawsgrifiad os byddwch eisiau tynnu'n ôl o'r astudiaeth yn ddiweddarach. Caiff yr holl ddata ei ddinistrio bum mlynedd ar ôl i'r astudiaeth ddod i ben. Bydd unrhyw wybodaeth a ddefnyddir mewn unrhyw adroddiad neu bapur a ysgrifennir am yr ymchwil yn ddienw, yn cynnwys dyfyniadau uniongyrchol o'r cyfweiliadau.

- 9. Pwy sy'n trefnu ac yn ariannu'r astudiaeth hon?** Dr Helen Aslett seicolegydd clinigol dan hyfforddiant ym Mhrifysgol Bangor sy'n gwneud yr ymchwil hwn dan oruchwyliaeth yr Athro Bob Woods (Athro Seicoleg Glinigol a Chyd-gyfarwyddwr Canolfan Datblygu Gwasanaethau Dementia Cymru), Dr Joanne Kelly-Rhind (seicolegydd clinigol) a Dr Jaci Huws (goruchwyliwr dulliau ymchwil). Ni chaiff yr astudiaeth hon ei hariannu gan gorff allanol.
- 10. Pwy sydd wedi adolygu moeseg yr astudiaeth hon?** Mae'r astudiaeth wedi'i hadolygu a'i chymeradwyo gan Bwyllgor Moeseg a Llywodraeth Ymchwil

Ysgol Seicoleg Prifysgol Bangor a chan Bwyllgor Moeseg Ymchwil a Phwyllgor Ymchwil a Datblygu Gogledd Cymru (Gorllewin).

11. Gyda phwy y dylwn gysylltu i gael rhagor o wybodaeth? Os oes gennych unrhyw gwestiynau ynglŷn â'r astudiaeth hon, neu os hoffech siarad â rhywun cyn cymryd rhan, ffoniwch Dr Helen Aslett ar 07546309221 rhwng 9am a 5pm, neu anfonwch e-bost i pspcb5@bangor.ac.uk neu ysgrifennwch ati yn Rhaglen Seicoleg Glinigol Gogledd Cymru, Ysgol Seicoleg, Prifysgol Bangor, Bangor, Gwynedd, LL57 2DG. Neu cysylltwch â'r Athro Bob Woods ar 01248 382463 neu b.woods@bangor.ac.uk

12. Cwynion: Os oes gennych unrhyw gwynion ynglŷn â'r ffordd y cynhaliwyd yr astudiaeth hon, cysylltwch â Hefin Francis, Rheolwr yr Ysgol Seicoleg, Prifysgol Bangor, Bangor LL57 2AS. Ffôn: 01248 388339

Diolch i chi am roi o'ch amser i ddarllen y daflen wybodaeth hon.

**RHAGLEN SEICOLEG CLINIGOL GOGLEDD CYMRU
NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME**

PARTICIPANT INFORMATION SHEET

1. **STUDY TITLE:** The experience of having a parent diagnosed with dementia before the age of 65.

2. **INVITATION:** We would like to invite you to take part in our research study which is trying to develop our understanding of the experiences of individuals who have a parent diagnosed with dementia before the age of sixty-five. This would involve taking part in an individual interview lasting approximately 45 minutes to one hour where you would discuss your experiences.
Before you decide whether or not to take part in this study it is important that you understand why it is being carried out and what it will involve. Please take time to read the following information sheet carefully and discuss it with friends or relatives if you wish. You should not feel under any obligation to take part in this study because you have been given this invitation. If there is anything that is not clear to you, or if you have any questions, please contact Dr Helen Aslett, the principal investigator on this project whose contact details are at the end of this sheet.
Thank you for reading this.

3. **What is the purpose of this study?** In this study we are seeking to gain a better understanding of the experiences of individuals who have a parent living with a dementia that was diagnosed before the age of 65. There is currently little research in this area and this is something that we hope to address. Whilst the purpose of this research is primarily educational it is hoped that the findings will be published to a wider audience. Recruitment to this study is across clinics within the Betsi Cadwaladr University Health Board.

4. **Why have I been invited?** Your parent or the person accompanying your parent to clinic in respect of their dementia thought you might be interested in learning more about this study and potentially taking part in it. We are contacting you to ask whether you would be willing to participate in an individual interview so that we can learn more about your experiences about having a parent with dementia diagnosed before the age of 65.

5. **Do I have to take part?** No, it is entirely up to you to decide whether or not to take part. If, having read the information sheet, you do not wish to take part you

may dispose of this information pack immediately. Whether you choose to take part in the study or not, will not affect any treatment offered to your parent or support offered to you in any way. Taking part in the study will however, help us to develop a greater understanding of the experiences of individuals whose parents have a dementia diagnosis before the age of 65. If you agree to take part in the study we would ask you to sign a consent form, but you are free to withdraw from the study at any time without giving a reason. Again this would not affect the care you or your parent receives.

- 6. What will happen to me if I take part?** If you decide to take part, please contact Dr Helen Aslett either by email at pspcb5@bangor.ac.uk, telephoning or sending a text message to 07546309221. If replying by email please make sure you include a telephone number. Dr Helen Aslett will then telephone you to arrange a time to come and talk to you about your experiences. The interview can either take place at the clinic where your parent receives medical support, at Bangor University or at your home, whichever is most convenient for you.

Before the interview you will be asked to sign a consent form to say that you understand the purpose of the study, your right to withdraw from it and any time and agreeing to the interview being audio recorded. The interview will last approximately 45 minutes to one hour, in which you will be asked to talk about your experiences of having a parent with a dementia diagnosis. The interview will be audio recorded, but your identity will remain confidential at all times. Please note that participants must be over 18 years of age. After the interview you will be offered a £10 gift voucher as a token for your participation in this study.

- 7. Are there any disadvantages, risks or benefits from taking part in this study?** We know of no disadvantages or risks associated with taking part. There may be no direct or immediate benefits to yourself from taking part, and the current study is for research purposes only, but there may be potential long-term benefits to taking part. Your contribution may help us to gain a greater understanding of issues facing individuals whose parents have a dementia diagnosis prior to the age of 65.

The interviews may touch on issues that give rise to concerns regarding your mood and well-being, particularly if you have never spoken to anyone about your experiences until now. If such issues arise during the interview we will

discuss possible sources of help and referral. You might also wish to contact one of the following support lines:

Alzheimers Society 0845 3000336 or Admiral Nursing Direct 0845 257 9406

Alternatively you might like to contact the clinical nurse specialist (CNS) at the clinic where your parent attends.

Dr Helen Aslett will also telephone you within 48 hours of being interviewed to check whether the interviews have prompted any issues for you and to check whether you are still happy for your interview to be included in the study.

- 8. Will my taking part in this study be kept confidential?** Yes. We will follow ethical and legal practice (Data Protection Act, 1988). All information about you will be handled in confidence. Your participation in the study will remain completely confidential. Only members of the research team (see Q9) will see the transcript of the interview. The audio recording of your interview will also be destroyed immediately after transcription by Dr Helen Aslett. The transcript will be made anonymous, password protected and stored on a password encrypted pen drive.

Your interview transcript will be assigned a unique code so that your name is not on any information you have provided and your consent form will be stored separately to your transcript so that it cannot be identified. The unique code will enable us to match your details to your transcript should you wish to withdraw from the study at a later date. All data will be destroyed five years after the completion of the research. Any information used in reports or papers about the research will be anonymised including direct quotations from the interviews.

- 13. Who is organizing and funding this study?** The research is being carried out by Dr Helen Aslett a trainee clinical psychologist at Bangor University, Wales under the supervision of Professor Bob Woods (Professor of Clinical Psychology and Co-Director Dementia Services Development Centre, Wales), Dr Joanne Kelly-Rhind (Clinical Psychologist) and Dr Jaci Huws (Research methods supervisor). This study is not being funded by an external body.
- 14. Who has reviewed the ethics of this study?** The study has been reviewed and approved by the Bangor University School of Psychology Research Ethics and Governance Committee and the North Wales Research Ethics and R&D Committees (West).

- 15. Who can I contact for further information?** If you have any questions about this project, or if you want to talk to somebody before taking part, please contact Dr Helen Aslett on 07546309221 between 9am-5pm, or email pspcb5@bangor.ac.uk or write to her at the North Wales Clinical Psychology Programme, School of Psychology, Bangor University, Bangor, Gwynedd. LL57 2DG. Alternatively please contact Professor Bob Woods on 01248 382463 or b.woods@bangor.ac.uk
- 16. Complaints:** If at any time you have any complaint about the way that the research has been conducted, please contact Hefin Francis, School Manager, School of Psychology, Bangor University, Bangor. LL57 2AS. Telephone 01248 388339.

Thank you for taking the time to read this information sheet.

RHAGLEN SEICOLEG GLINIGOL GOGLEDD CYMRU

NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME

TAFLEN WYBODAETH I GYFRANOGWYR

1. **TEITL YR ASTUDIAETH:** Y profiad o fod â rhiant sydd wedi cael diagnosis o ddementia cyn 65 oed.

2. **GWAHODDIAD:** Hoffem eich gwahodd i gymryd rhan yn ein hastudiaeth ymchwil sy'n ceisio cynyddu ein dealltwriaeth o brofiadau pobl sydd â rhiant sydd wedi cael diagnosis o ddementia cyn 65 oed. Bydd hyn yn golygu cymryd rhan mewn cyfweiliad unigol fydd yn para rhwng tri chwarter awr ac awr i drafod eich profiad.

Cyn ichi benderfynu a hoffech gymryd rhan, mae'n bwysig eich bod yn deall pam rydym yn gwneud yr astudiaeth a beth fydd yn digwydd. Cymerwch amser i ddarllen y daflen wybodaeth isod yn ofalus a'i thrafod â ffrindiau neu berthnasau os dymunwch. Ni ddylech deimlo unrhyw reidrwydd i gymryd rhan yn yr astudiaeth hon oherwydd y gwahoddiad hwn. Os ydych yn ansicr ynglŷn â rhywbeth, neu os oes gennych unrhyw gwestiynau, cysylltwch â Dr Helen Aslett, prif ymchwilydd yr astudiaeth hon. Mae ei manylion cyswllt ar waelod y daflen hon.

Diolch i chi am ddarllen hwn.

3. **Beth yw diben yr astudiaeth hon?** Yn yr astudiaeth ymchwil hon rydym yn ceisio cynyddu ein dealltwriaeth o brofiadau pobl sydd â rhiant sy'n byw gyda dementia ac a gafodd y diagnosis o ddementia cyn 65 oed. Ar hyn o bryd nid oes llawer o ymchwil wedi ei wneud yn y maes hwn ac mae hyn yn rhywbeth yr ydym yn gobeithio ei newid. Er mai at ddibenion addysgol y gwneir yr astudiaeth hon yn bennaf, gobeithir y caiff y canlyniadau eu cyhoeddi ac y byddant ar gael i gynulleidfa fwy. Caiff cyfranogwyr eu recriwtio i'r astudiaeth hon trwy glinigau Bwrdd Iechyd Prifysgol Betsi Cadwaladr.

4. **Pam wyf wedi cael gwahoddiad?** Roedd eich rhiant neu'r sawl oedd wedi dod gyda'ch rhiant i'r clinig dementia yn credu y byddai gennych ddi-ddordeb gwybod mwy am yr astudiaeth ac efallai cymryd rhan ynddi. Rydym yn cysylltu â chi i ofyn a fyddech yn fodlon cymryd rhan mewn cyfweiliad unigol er mwyn inni ddysgu mwy am eich profiad o fod â rhiant sydd wedi cael diagnosis o ddementia cyn 65 oed.

5. A oes rhaid imi gymryd rhan? Nac oes, chi sydd i benderfynu a ydych am gymryd rhan yn yr astudiaeth. Os na fyddwch yn dymuno cymryd rhan ar ôl darllen y daflen wybodaeth hon, gallwch daflu'r pecyn gwybodaeth hwn ar unwaith. Ni fydd eich penderfyniad i gymryd rhan neu beidio yn yr astudiaeth hon yn effeithio mewn unrhyw ffordd ar y driniaeth a gynigir i'ch rhiant nac ar y gefnogaeth a gynigir i chi. Ond os cymerwch ran yn yr astudiaeth, bydd hynny'n gymorth i ni gynyddu ein dealltwriaeth o'r profiad o fod â rhiant sydd wedi cael diagnosis o ddementia cyn 65 oed. Os byddwch yn cytuno i gymryd rhan yn yr astudiaeth, byddwn yn gofyn i chi lofnodi ffurflen gydsynio, ond gallwch dynnu'n ôl o'r astudiaeth ar unrhyw adeg a heb roi rheswm. Ni fyddai hynny'n effeithio ar safon y gofal yr ydych chi neu eich rhiant yn ei gael.

6. Beth fydd yn digwydd i mi os byddaf yn cymryd rhan? Os penderfynwch gymryd ran, cysylltwch â Dr Helen Aslett naill ai trwy anfon e-bost i pspcb5@bangor.ac.uk neu trwy ffonio neu anfon neges destun i 07546309221. Os byddwch yn anfon e-bost, cofiwch gynnwys rhif ffôn yn eich neges. Wedyn bydd Dr Helen Aslett yn eich ffonio i drefnu amser i ddod i siarad â chi am eich profiad. Gellir cynnal y cyfweiliad yn y clinig lle mae eich rhiant yn cael cefnogaeth feddygol, ym Mhrifysgol Bangor neu yn eich cartref, pa bynnag un sydd fwyaf cyfleus i chi.

Cyn y cyfweiliad gofynnir i chi lofnodi ffurflen gydsynio i ddweud eich bod yn deall diben yr astudiaeth, eich hawl i dynnu'n ôl o'r astudiaeth ar unrhyw adeg a'ch bod yn cytuno i'r cyfweiliad gael ei recordio ar dâp sain. Bydd y cyfweiliad yn para rhwng tri chwarter awr ac awr ac yn ystod y cyfweiliad gofynnir i chi drafod eich profiad o fod â rhiant sydd wedi cael diagnosis o ddementia. Caiff y cyfweiliad ei recordio ar dâp sain, ond caiff eich manylion personol eu cadw'n gyfrinachol trwy'r amser. Mae'n rhaid i gyfranogwyr fod dros 18 oed. Ar ôl y cyfweiliad, ceuwch daleb gwerth £10 i ddiolch i chi am gymryd rhan yn yr astudiaeth hon.

7. A oes unrhyw anfanteision, risgiau neu fanteision o gymryd rhan yn yr astudiaeth hon? Nid ydym yn gwybod am unrhyw anfanteision na risgiau sy'n gysylltiedig â chymryd rhan. Ac er na fydd unrhyw fanteision uniongyrchol i chi efallai ac y gwneir yr astudiaeth at ddibenion ymchwil yn unig, efallai y bydd manteision tymor hir i chi o gymryd rhan. Ond mae'n bosib y bydd eich cyfraniad yn gymorth i ni ddeall y problemau sy'n wynebu pobl sydd â rhiant sydd wedi cael diagnosis o ddementia cyn 65 oed.

Mae'n bosib y bydd y cyfweiliadau'n cyffwrdd â materion fydd yn arwain at bryder am eich hwyliau a'ch lles, yn enwedig os na fyddwch wedi siarad am eich profiadau erioed o'r blaen. Os bydd materion o'r fath yn codi yn ystod y cyfweiliad, byddwn yn sôn wrthyhych am ffynonellau cymorth posib ac yn eich cyfeirio atynt. Efallai y byddwch eisiau cysylltu ag un o'r llinellau cymorth canlynol hefyd:

Alzheimers Society 0845 3000336 neu Admiral Nursing Direct 0845 257 9406
Gallech hefyd gysylltu â'r nyrs glinigol arbenigol yn y clinig y mae eich rhiant yn mynd iddo.

Bydd Dr Helen Aslett hefyd yn eich ffonio cyn pen 48 awr ar ôl y cyfweiliad i sicrhau nad yw'r cyfweiliad wedi gwneud ichi ddechrau meddwl am bethau sy'n peri pryder i chi ac i holi a ydych yn dal yn fodlon i'ch cyfweiliad gael ei gynnwys yn yr astudiaeth.

- 8. A fydd y ffaith fy mod yn cymryd rhan yn yr astudiaeth hon yn cael ei chadw'n gyfrinachol?** Bydd. Byddwn yn dilyn arferion moesegol a chyfreithiol (Deddf Diogelu Data, 1988). Caiff yr holl wybodaeth amdanoch chi ei thrin yn gyfrinachol. Bydd eich cyfraniad at yr astudiaeth yn aros yn gwbl gyfrinachol. Dim ond aelodau'r tîm ymchwil (gweler cwestiwn 9) fydd yn cael gweld y trawsgrifiad o'r cyfweiliad. Caiff y tâp sain o'ch cyfweiliad ei ddinistrio yn syth ar ôl i Dr Helen Aslett ei drawsgrifio. Caiff eich manylion personol eu tynnu o'r data fel na fydd modd eich adnabod, caiff y data ei gadw ar gof bach wedi ei amgryptio gyda chyfrinair.

Rhoddir cod unigryw ar eich trawsgrifiad fel na chysylltir eich enw â'r wybodaeth ynddo a chaiff eich ffurflen gydsynio ei chadw ar wahân fel na fydd modd ei chysylltu â'r trawsgrifiad. Bydd y cod unigryw yn caniatáu i ni baru eich manylion gyda'ch trawsgrifiad os byddwch eisiau tynnu'n ôl o'r astudiaeth yn ddiweddarach. Caiff yr holl ddata ei ddinistrio bum mlynedd ar ôl i'r astudiaeth ddod i ben. Bydd unrhyw wybodaeth a ddefnyddir mewn unrhyw adroddiad neu bapur a ysgrifennir am yr ymchwil yn ddienw, yn cynnwys dyfyniadau uniongyrchol o'r cyfweiliadau.

- 13. Pwy sy'n trefnu ac yn ariannu'r astudiaeth hon?** Dr Helen Aslett seicolegydd clinigol dan hyfforddiant ym Mhrifysgol Bangor sy'n gwneud yr ymchwil hwn dan oruchwyliath yr Athro Bob Woods (Athro Seicoleg Glinigol a Chyd-gyfarwyddwr Canolfan Datblygu Gwasanaethau Dementia Cymru), Dr Joanne Kelly-Rhind (seicolegydd clinigol) a Dr Jaci Huws (goruchwyliwr dulliau ymchwil). Ni chaiff yr astudiaeth hon ei hariannu gan gorff allanol.

- 14. Pwy sydd wedi adolygu moeseg yr astudiaeth hon?** Mae'r astudiaeth wedi'i hadolygu a'i chymeradwyo gan Bwyllgor Moeseg a Llywodraeth Ymchwil Ysgol Seicoleg Prifysgol Bangor a chan Bwyllgor Moeseg Ymchwil a Phwyllgor Ymchwil a Datblygu Gogledd Cymru (Gorllewin).
- 15. Gyda phwy y dylwn gysylltu i gael rhagor o wybodaeth?** Os oes gennych unrhyw gwestiynau ynglŷn â'r astudiaeth hon, neu os hoffech siarad â rhywun cyn cymryd rhan, ffoniwch Dr Helen Aslett ar 07546309221 rhwng 9am a 5pm, neu anfonwch e-bost i pspcb5@bangor.ac.uk neu ysgrifennwch ati yn Rhaglen Seicoleg Glinigol Gogledd Cymru, Ysgol Seicoleg, Prifysgol Bangor, Bangor, Gwynedd, LL57 2DG. Neu cysylltwch â'r Athro Bob Woods ar 01248 382463 neu b.woods@bangor.ac.uk
- 16. Cwynion:** Os oes gennych unrhyw gwynion ynglŷn â'r ffordd y cynhaliwyd yr astudiaeth hon, cysylltwch â Hefin Francis, Rheolwr yr Ysgol Seicoleg, Prifysgol Bangor, Bangor LL57 2AS. Ffôn: 01248 388339

Diolch i chi am roi o'ch amser i ddarllen y daflen wybodaeth hon.

Centre Number:
Study Number:
Participant identification number:

CONSENT FORM

Title of Project: The experience of having a parent diagnosed with dementia before the age of 65.

Name of Researcher: Dr Helen Aslett

**Please
initial box**

1. I confirm that I have read and understood the information sheet dated 24.01.2012 v1.2 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily
2. I understand that my participation in this study is completely voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or that of my family being affected
3. I understand that for the purposes of this study I will be required to be interviewed and that this interview will be audiotaped. I give permission for the interview to be audiotaped.
4. I understand that all data I provide will be made anonymous and kept in the strictest of confidence in accordance with the Data Protection Act 1988.
5. I understand that anonymised direct quotations may be used from my anonymised interview in reports and publications arising from the study.
6. I agree to take part in the above study.

Name of participant

Date

Signature

Name of person taking
Consent

Date

Signature

When completed: 1 for participant; 1 for researcher site file.

Appendix 4: Interview topic guide

Interview Schedule

Please tell me what having a parent with a dementia diagnosis means to you?

(Participants will be made aware that the themes raised by the answer to this question will be addressed individually)

Other areas to cover in the interview:

When you first heard about the diagnosis, what happened?

Prompt: What did you think? How did you feel?

For you, what impact has the diagnosis had on your life?

Prompt: What do you think about this? How has this made you feel?

How has the diagnosis impacted on other family member?

Prompt: What do you think about this? How has this made you feel?

To what extent has your relationship with [parent with YOD] changed since they were diagnosed?

Primary prompts: In what ways has it changed? What was your relationship like with them prior to diagnosis?

Secondary prompts: What do you think about this? How has this made you feel?

To what extent has your relationship with other family members changed since the diagnosis?

Primary prompts: In what ways has it changed? What was your relationship like with them prior to diagnosis?

Secondary prompts: What do you think about this? How has this made you feel?

To what extent has your relationship with your friends changed since the diagnosis?

Primary prompts: In what ways has it changed? What was your relationship like with them prior to diagnosis?

Secondary prompts: What do you think about this? How has this made you feel?

To what extent has your relationship with your partner changed since the diagnosis?

Primary prompts: In what ways has it changed? What was your relationship like with them prior to diagnosis?

Secondary prompts: What do you think about this? How has this made you feel?

How has the diagnosis changed your outlook on life?

Primary prompts: In what ways has it changed? Are you more concerned about your own well-being since this diagnosis?

Secondary prompts: What do you think about this? How does this make you feel?

How do you feel about the future?

Prompts: What concerns do you have? How does this make you feel?

Other prompts to use:

I'm hearing that...

I'm wondering if...

At the end of the interview allow participants the opportunity to add, raise or clarify issues

Appendix 5: Example of IPA transcript coding

Excerpt from interview with Kate

This is the first 7 pages of the coded transcript of Kate.

KEY

INT: Interviewer

RES: Respondent

s.l. Sounds like

... = pause

[...] = material omitted

[nurse] = explanatory material added

IPA coding:

In comments column:

Normal text = descriptive code

Italics = linguistic code

Underlined = conceptual code

Asterix* = personal reflection

Emergent themes	Original Transcript	Initial thoughts/ exploratory comments
<p>Relentless</p> <p>Approach to diagnosis</p> <p>Role reversal</p> <p>Loss</p> <p>Loss / Reaction</p> <p>Self as responsible / guilt</p> <p>Feeling responsible</p>	<p>INT: Erm, so maybe just start off telling me what ... what it's like?</p> <p>RES: Erm ... a nightmare. It doesn't end. We just take each day as it comes, but it's horrible.</p> <p>INT: Mm. [<i>Unclear – 0:00:30</i>]. Tell me a bit more about ...</p> <p>RES: <u>Its just seeing someone that you love so much</u>, like ... they are the ones that erm ... <u>oh I don't know, you just look up to them for all your life and then now they're looking to you for help.</u></p> <p>INT: Mm.</p> <p>RES: <i>And they've just gone</i>, that's ... that's the worst part about it. That ... yeah it's just ... that's all I can say really, it's just a living nightmare. I hate it.</p> <p>INT: How old were you when your Dad was diagnosed?</p> <p>RES: Erm ... I was twenty-five when he was first diagnosed. Erm, but it went so quick; he went into hospital with ... erm, he had internal bleeding, and <u>I thought for years he had depression</u>. So he went into hospital with internal bleeding, he found out he had diabetes. Erm, and two weeks after they transferred him over to mental health, so everything just went too quick and <u>it was only when I came out of work that I actually realised how bad he was.</u></p> <p>INT: Mm.</p> <p>RES: <u>I thought he was depressed, and clearly he didn't know what day of the week it was or what was going on in the news, so ... difficult.</u></p> <p>INT: Mm. It sounds like it all happened very ...</p> <p>RES: Fast.</p>	<p>description of how they live with the diagnosis <i>Sense of the relentless nature of her dad's condition.... "nightmare", "doesn't end", "horrible",</i></p> <p>Describing the relationship change <u>Feelings of pain/heartbreak at what is happening. Sense of injustice-roles should not have been reversed</u></p> <p><i>They have just gone – sense of being alone</i> <u> Losing a sense of who her dad is. What does this mean to her? living nightmare, hate it...emphasis of the negative impact</u></p> <p>Timeline of events <u>Is there an element of self-blame, that she hadn't recognised the symptoms and their severity? Guilt?</u></p> <p><u>What is the issue here? Self as responsible? Guilt? Trying to make sense of what is happening</u></p>

<p>Impact of diagnosis</p>	<p>INT: ... quickly.</p> <p>RES: Yeah it was. Too fast, err ... you just, oh I don't know, it just ... <i>knocks you about. It's knocked me about</i>, I still am as well, so ...</p> <p>INT: Yeah. How long ago was that?</p> <p>RES: Erm ... we're looking at ... well, April ... oh, well ... it'd be 2012 was when he went into hospital ... and he hasn't come out since.</p> <p>INT: Right.</p> <p>RES: So he went straight into [hospital name]; two weeks after he got transferred into mental health, and then ... [name of] Nursing Home now, where he is now.</p>	<p>Timeline <i>Physical force terms to explain the impact, gives a sense that it's a battle, a fight</i></p> <p>Timeline</p> <p>Timeline – rapid deterioration</p>
<p>Feeling unsupported</p>	<p>INT: Mm.</p> <p>RES: So he hasn't come out for ... he had a break where it was a week, and then I had no support ... and then he had to go back. And then they said he wasn't coming back home.</p>	<p>Lack of support when dad came out of hospital.</p>
<p>Unsupported/isolated</p>	<p>INT: When you say you had no support ...?</p> <p>RES: No support off Social; it's probably the worst experience I've ever had, especially with me because <i>I'm by myself</i>. Like my Mum and Dad divorced, my Dad's got <i>no family, no brothers</i> and sisters, <i>no Mum and Dad</i> erm ... they promised me the world and they ... they let me down. So Social Services, they're support of it ... poor, really poor.</p> <p>INT: Mm. Mm. So you say your ... your Mum and Dad ...</p> <p>RES: Divorced, yeah.</p> <p>INT: ... divorced, is your Mum ... does she ...?</p> <p>RES: Yeah my Mum still ... does a lot with him.</p> <p>INT: Yeah.</p>	<p>No support from statutory services. <u><i>Sense of isolation, Feelings of being let down, by services and situation and her mum</i></u></p> <p>Dissatisfaction with services</p>

<p>Self-responsibility/guilt</p>	<p>RES: Erm ... but she's remarried now. But it was ... it was round about when they split up that he really went downhill, I noticed the depression.</p> <p>INT: Mm.</p> <p>RES: <u>But clearly it was dementia but I ... misdiagnosed it, unfortunately.</u> So ...</p> <p>INT: So when ... when would ... when did the depression ...?</p> <p>RES: The depression started pretty much straightaway. My Mum and Dad have been divorced for six years, and it was a messy divorce. Erm ... and it was just trying to pick up the pieces really, but he never did. And he ... his business started going downhill, because he was a driving instructor. Erm ... wasn't making enough money, started forgetting about jobs, started forgetting to do stuff round the house. He was just ... people were saying things, that he was doing stuff that was strange to them, repeating himself quite a lot. <u>And I thought it was depression,</u> and the first day I took him to the doctors he got rushed into hospital, so its err ... yeah it all happened pretty quick. <u>And then till I took the time out of work to actually realise it was ... worse than what it was, I thought right, I've been living with this for a couple of years, but I would literally just come straight back home from work, have my tea, have a bath, go straight to bed.</u></p>	<p><u>Is there a sense of her seeing mum or the stress of the marital breakdown as being partly responsible for dad's illness?</u></p> <p><u>Sense of failed duty, responsibility, but was it within her capability to diagnose it? How was it clear?</u> <i>Use of the word "Misdiagnosed" suggests she sees herself as someone who should have known how to diagnose it</i></p> <p>The impact that divorce had on her father's life. Description of how her dad deteriorated cognitively.</p>
<p>Self-responsibility guilt</p>	<p>INT: Mm.</p> <p>RES: <u>And I wouldn't even acknowledge ...</u></p>	<p><u>Sense of blaming self</u> <u>Sense of time</u></p> <p><u>Does she feel responsible for not recognising the symptoms earlier?</u> <u>Does she perceive herself to have deliberately ignored the situation.</u></p>
<p>Avoidance</p>	<p>INT: So you ...</p> <p>RES: ... <u>what was wrong with him.</u></p>	<p><u>Is she suggesting that she knew something was going on, but didn't want to confront it?</u></p>
<p>Avoidance</p>	<p>INT: So you were living ...</p> <p>RES: <u>I sort of like avoided it.</u></p>	

<p>Strength of relationship with YOD parent</p>	<p>INT: ... with your Dad at the time?</p> <p>RES: Yeah. Yeah, I always lived with him.</p> <p>INT: Mm.</p> <p>RES: So I've all ... this has always been <i>our house together</i>; it was Mum and Dad's at first and then she left ...</p> <p>INT: Mm.</p>	<p><u>Managed the changes in her dad, by ignoring it. But could she have actually picked up on the changes?</u></p> <p>The close bond between her and her dad</p> <p><i>Emphasis on dad and her as a combined unit, mum on the outside</i></p>
<p>Relationship with other parent</p>	<p>RES: ... my Dad kept the house on, didn't want to give it to <i>her</i>, he said '<i>This is our house</i>', and I've always stayed here with him. So yeah, I was living with it, yeah.</p>	<p><i>"her" depersonifying her mum yet using "our" emphasises the bond between her and her dad</i></p>
<p>Relationship with YOD parent</p>	<p>INT: Mm. So you said about ... how it all happened very quickly ...</p> <p>RES: Yeah.</p> <p>INT: ... you went ... was it you that encouraged your Dad to go to the doctors?</p> <p>RES: I tried to encourage him to go to the doctors but he was ... if ... if you ... people like you would have actually known my Dad, he's very hard ... he's very hard faced and he's ... he's difficult to take anywhere. If you said 'Go to the doctors and have a blood test' he's pretty much like ... 'No', <i>but I'm the same</i>, I'd run a mile if they said blood tests, I'd be like 'No, it's alright, I'll come back another day and do it'. But my Dad was one of them, he hated going to the doctors for anything. Erm, but he was difficult to take. And then this one day he said 'Yeah okay I'll go', and I thought 'What the hell ...?', I just couldn't work out what was wrong with him, I thought 'Why does he want to go to the doctors today?'. And I took him down there and he got rushed into hospital with ... well, bleeding, internal bleeding, and they done a couple of questions with him and ... <i>I just broke down then because I thought 'Wow, how bad is this?'. Err, yeah, hard.</i></p>	<p>Describing her dad's personality prior to illness. Gives a sense of his character as someone who doesn't like to make a fuss, knows his own mind.</p> <p>Comparing herself to her dad</p> <p>Describing how dad came to get medical help.</p>
<p>Similarity with YOD parent</p> <p>Reaction to/ impact of diagnosis on self</p>	<p>RES: I tried to encourage him to go to the doctors but he was ... if ... if you ... people like you would have actually known my Dad, he's very hard ... he's very hard faced and he's ... he's difficult to take anywhere. If you said 'Go to the doctors and have a blood test' he's pretty much like ... 'No', <i>but I'm the same</i>, I'd run a mile if they said blood tests, I'd be like 'No, it's alright, I'll come back another day and do it'. But my Dad was one of them, he hated going to the doctors for anything. Erm, but he was difficult to take. And then this one day he said 'Yeah okay I'll go', and I thought 'What the hell ...?', I just couldn't work out what was wrong with him, I thought 'Why does he want to go to the doctors today?'. And I took him down there and he got rushed into hospital with ... well, bleeding, internal bleeding, and they done a couple of questions with him and ... <i>I just broke down then because I thought 'Wow, how bad is this?'. Err, yeah, hard.</i></p>	<p>Impact of diagnosis. <i>Sense of enormity, feeling overwhelmed.</i></p>

<p>Reaction to/impact of diagnosis on self</p>	<p>INT: When did it hit you then that ... do you think ... when ... well when, when did you think oh, this isn't just depression, this is ...?</p> <p>RES: When I was actually in the hospital the doctor come round and ... they ... they asked him about a number of questions; it was just general information that you should know like the ... today's date, the date ... what month are we in, and ... it was ... write quotes and spell 'world' backwards, and ... this is something, we're talking, like a really clever man that should have known it all, <u>and that's when it hit and I just broke down, I thought 'Oh my God, what do I do now?'</u>.</p>	<p>Emphasising what her dad was like pre diagnosis, the difference and the decline.</p> <p><u>The impact of the diagnosis, the realisation of what is happening to her dad.</u> Sense of helplessness</p>
<p>Coping v not coping</p>	<p>INT: Mm.</p> <p>RES: Err, yeah <i>its hard</i>.</p> <p>INT: Okay. And I guess it's hard because everything's changed in your home ...</p> <p>RES: Yeah.</p> <p>INT: ... home life, yeah.</p>	<p>It's not easy being in this position</p>
<p>Coping v not coping</p>	<p>RES: Yeah <i>it's hard</i>. Yeah but its ... <u>you never get used to it</u>. People always say it's going to get worse, and you just ... it is like <i>living in a nightmare</i>. It's sort of like ... <u>I don't know, cancer, you've got so much support for it, and you ... you know everything about it, but dementia, it just ... takes that loved one away from you and its horrible.</u></p>	<p>What would "getting used to it" mean? Would that be acceptance? <i>Language used to express the reality of her dad's diagnosis – "hard"; "living in a nightmare"; "horrible" sense that dementia is "taking" her father from her. Sense of isolation and of being alone. Is there a feeling that dementia is the poor relation to cancer and there is no support. Feeling of loss, that dementia is stealing (taking) the person from their family</i></p>
<p>Adjustment</p>	<p>INT: Mm.</p> <p>RES: Especially for the age he is.</p> <p>INT: How old is your ...?</p> <p>RES: <u>He's err, fifty-three. So ... yeah, fifty-three [upset]. Yes, [unclear – 0:07:29].</u></p>	<p><i>*Important for me as the interviewer to reflect on my own feelings at this point and issues raised</i></p>
<p>Comparing to other illnesses</p>	<p>INT: Mm.</p> <p>RES: Especially for the age he is.</p> <p>INT: How old is your ...?</p> <p>RES: <u>He's err, fifty-three. So ... yeah, fifty-three [upset]. Yes, [unclear – 0:07:29].</u></p> <p>INT: It's alright, just take your time.</p>	<p><u>Sense of realisation of how young her dad is, seems to emphasize the feelings of loss.</u></p>

<p>Impact of diagnosis</p> <p>Sense of duty</p> <p>Loss</p> <p>Sense of duty</p> <p>Isolation</p> <p>Burden</p> <p>Life on hold</p> <p>Social comparison</p> <p>Loss of self /life on hold</p>	<p>RES: Yeah it's fine. Yeah, so he's fifty-three. They said within an eighteen month period they would start to see him go down. <i>And he's gone ... he went into hospital talking, and he doesn't speak at all now. He's got no facial expression. He's on soft food, so they've took him away from solid foods to soft foods. Err ... he's erm ... yeah it's difficult. And I know I haven't got to deal with it, but seeing him ... it's hard. It's ... some days I just don't even want to go there ... because I know it's not him anymore ... and I feel bad [upset].</i></p> <p>INT: How often do you manage to ...?</p> <p>RES: I go every day, yeah whether I feel erm ... but I know it's when he's having a bad day, I ... <i>I don't want to be there myself.</i> Like when he was in the hospital I'd go every other, because he's only down the road now I have to ... <i>I feel like I have to go every day and see him. Erm ... because he's got no-one else to go, there's no family for him to go and see or ... anyone to go and see him, it's ... it's all on me. My Mum goes ... maybe twice, maybe once, twice a week, but ... everything is all on me ... and I've got no-one to share it with brother and sister-wise. So it's everything is solely on me.</i></p> <p>INT: And I'm guessing that ... can be ...?</p> <p>RES: Yeah, draining. But yeah, but ... yeah if I've had ... I feel like I've had enough lately, I just ... I don't feel like a normal twenty-seven should do. I just feel like too much things have changed and ... you know, I ... I should be out there living my life, enjoying stuff, and I just don't feel like I've had that opportunity to. So it's ... yeah its bad.</p> <p>INT: When you say you feel like you've had enough ...</p> <p>RES: I don't know, it's ...</p> <p>INT: ... are you happy to talk a bit more ...?</p> <p>RES: Yeah I just feel I really ... like I don't feel like ... my normal self at all. Like ... like where I should be out having a good time, I just</p>	<p>Stages of loss- of function for her dad, and loss of her dad as she knew him <i>"and he's gone", "it's not him anymore" - the finality, sense of helplessness</i> <u>Comparing her experience to that of her dad's, downplaying how difficult it is for herself, a sense that she shouldn't complain.</u> <u>A real sense of a feeling of duty and obligation tied in with guilt.</u> <u>Is she feeling bad about not wanting to go and visit her dad, bad about what is happening to him or a combination of the two?</u> <u>Experience of loss.</u></p> <p>Seeing her dad as he is, is a struggle, sense of obligation and duty.</p> <p><u>There is a real sense of isolation, having to manage on her own, shoulder all of the responsibility.</u></p> <p><i>Feeling of the burden on her- "everything is all on me", everything is solely on me"</i></p> <p><u>What is "normal"? Questioning self? A sense of loss and envy for what she could be doing, sees her peers doing. Sense that her own life is on hold. Is she feeling the opposite emotions to those she is describing e.g. living, enjoying?</u> <u>How does she manage, the restrictions placed on her life? Are there restrictions on her life or is it her sense of duty and obligation that is making her feel like this?</u></p> <p>Feelings of depression as a result of her dad's illness <u>Questioning self. Questioning identity. Loss of identity, sense of who she is?</u></p>
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<p>Psychological impact</p> <p>Attitude to support groups</p> <p>Avoidance</p> <p>Isolation</p> <p>Loss</p> <p>Isolation /unsupported Life on hold</p> <p>Comparing self to affected parent</p> <p>Nobody understands – rejection of empathy</p> <p>Peer communication</p> <p>Coping v not coping distance</p> <p>Isolating self</p> <p>Impact of diagnosis</p>	<p>feel like I can't do it anymore, I just feel like really ... depressed ... stressed, because that's what I am.</p> <p>INT: Have you ... have you sought support from ... your GP?</p> <p>RES: No. This is the only thing with me, I don't talk about things, that's my problem. I wouldn't go ... I mean I've had time off work, I've had ... through everything, almost about twelve months off work, trying to get my head round things. But I also had two operations during that time as well. Erm ... but I've never been to a support group. Erm ... I kind of like avoid them, because I just feel like there's got to be worse situations out there, but then I know that the situation that we're in is very rare. You know, it's ... usually like, you know, my Mum should be dealing with this, but she isn't, <i>it's all on me.</i></p> <p>INT: Mm.</p> <p>RES: And I feel like it's worse for me as well because he's got no Mum and Dad, he's got no brothers or sisters, he's got no further distant family that would actually bother with him, so everything is all me. But yeah, <u>I feel like my life's been taken away from me at the moment.</u></p> <p>INT: How are your friends ... are you support ... do your friends ...?</p> <p>RES: Yeah they ... they do, they find it very hard to talk to me though because I ... I ... <i>I'm very similar to my Dad, like hard faced, where I don't like talking about things.</i> Like people always ask me work 'Oh you must be going through a really bad time, I understand', well you're never going to understand until you're in my position, and that really gets my back up. But it ... it's difficult, I mean what do you say to people? You know, it's ... its ... it is hard. I've never talked about it, I've just always said like, you know, 'I'm not having a good day today, leave me alone', or ... <u>I'll sort of like distance myself, but I will never say like 'This is killing me inside'. And it is, but I ... I don't talk about it to my friends because I just feel like that's something that people don't need to know.</u></p>	<p>Coping strategies she usually uses. Description of own health problems.</p> <p><u>Does she not see her own experiences as being valid? Downplaying her own experience? Is this a way of her coping with her situation? Is avoiding talking about her experience also a way of coping?</u></p> <p><u>Again, is there a feeling of resentment towards her mum, does she feel abandoned by mum?</u> <i>Implied sense of burden and isolation "it's all on me"</i></p> <p>Isolating experience of not having anyone to turn to in the family for support. <i>Sense of pressure "everything is all me".</i></p> <p><u>Is she feeling that his is not the only life which is being lost in this, that there are two victims: her and him?</u></p> <p>Description of peer support and communication with others <i>Emphasis on how her and her dad are alike, the bond between them</i> <u>Feeling of being misunderstood, that people can only understand what she has been through if they have experienced the same thing, yet does not want to be in a support group where she would meet people in a similar situation</u> <u>Anger at others responses to her, but also sense of not knowing what to say</u> Ways of managing such situations, avoidance, distancing. <u>Is there a sense that she doesn't want people to know or a sense that she feels others are prying or a belief that they won't understand?</u> <u>Isolating self</u> <i>This is killing me inside – base emotion of how she feels and how difficult it all is.</i></p>
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Appendix 6: Interview themes

Interview Themes arising from the IPA analysis

Super-ordinate them	Sub-ordinate theme	Sub-themes
“Like I know them, but I don’t know who they are”	“ <i>And they’ve just gone, that’s...that’s the worst part</i> ”	<ul style="list-style-type: none"> • Parent not able to fulfil parental role • Loss of knowing the parent as they used to know them • Parent becoming a shell • Relationship quality • Pre diagnosis relationship quality • Social comparison of peers relationships with their parents
	“ <i>You are sort of treading on eggshells</i> ”	<ul style="list-style-type: none"> • Patience • Frustration • Cognitive inflexibility/set-shifting • Unpredictable communication • Comprehension/understanding • Trying to understand what parent is thinking
“You just look up to them for all your life and then now they’re looking to you for help”	“ <i>I never thought I’d be doing for her</i> ”	<ul style="list-style-type: none"> • Impact of role change • Adaptation to role change • Views on role change • Assuming the parent role • Parent becoming infantilised • Loss of role for parent • Maintaining dignity in presence of role change
	“ <i>It’s kind of on hold at the moment</i> ”	<ul style="list-style-type: none"> • Restrictions on own life • Life on hold • Being held back • Giving up own career
	“ <i>It’s splitting me</i> ”	<ul style="list-style-type: none"> • Juggling responsibilities • Guilt associated with caring role • Caregiver burden • Coping versus not coping
“I feel like she can get things off her chest”		<ul style="list-style-type: none"> • Parental caregiver burden • Supporting parent • Awareness of impact of YoD on healthy parent • Powerlessness versus becoming the strong one • Pre-existing relationship dynamic
		<ul style="list-style-type: none"> • Communication with peers • Being understood versus nobody understanding • Rejection of empathy • Shared experiences • Formal support

Super-ordinate them	Sub-ordinate theme	Sub-themes
“Hang on a minute, this could happen to...to me”	<i>“It just knocks you about”</i>	<ul style="list-style-type: none"> • Physical impact of the diagnosis • Preconceptions about dementia being challenged • Realisation of own potential risk of YOD • Future planning • Attitude to genetic testing
	<i>“You only live once”</i>	<ul style="list-style-type: none"> • Living in the moment • Escaping responsibilities • Leading a valued life in spite of own risk • Defiance against dementia

Appendix 7: Word Count

Abstract		275	
Section 1	Title page	NA	
	Submission guidelines	NA	
	Abstract	156	
	Literature review	7815	
	Tables		100
	References		1660
Section 2	Title page	NA	
	Submission guidelines	NA	
	Abstract	130	
	Research paper	6982	
	Tables		174
	References		764
Section 3	Contributions to theory and practice	3357	
	Personal reflection	1000	
			827
Section 4	NHS Ethics and R&D approval	NA	
Appendix 1	Review paper quality checklist		425
Appendix 2	Summary of literature review		1848
Appendix 3	papers		6454
Appendix 4	Participant information sheets, letters of invite and consent form		381
Appendix 5	Interview topic guide		3340
Appendix 6	Example of IPA transcript coding		315
	Interview themes		
Sub totals		19715	16288
TOTAL WORD COUNT			36003

