



## Exploring Relationship Challenges Caused By Behavioural-Variant Frontotemporal Dementia

We would like to invite you to take part in our research. We would like to speak with spouses or long-term partners of individuals with a diagnosis of Behavioural-Variant Frontotemporal Dementia (bvFTD), specifically those who have experienced change within their relationship and within their partner. This may include:

- **Changes in personality** (irritable, blunt, lacking sympathy, impulsive, not doing much, change in humour, emotional outbursts, other unpleasant traits)
- **Changes in behaviour** (shouting, swearing, acting inappropriately in public, aggression, 'no filter', making social 'faux pas')

### What is the purpose of this research?

The aim of this research is to explore relationship changes within the context of bvFTD. This can be a tough diagnosis, especially for partners or spouses. bv-FTD can cause significant changes in personality and behaviour, and this may affect, or change, relationships. At the moment, we don't know exactly what it is that partners and spouses may find difficult about these behaviours and personality changes and how this influences the relationship between partners.

The wellbeing of carers is important. We hope that by speaking to the partners and spouses of people living with bv-FTD, we can identify the best way to support their mental health.

This research also forms parts of a Clinical Psychology doctoral thesis at the University of Birmingham.

### Why have I been invited to take part?

You have been invited to take part because you are the spouse or long-term partner of someone with bvFTD.

### What would taking part involve for me?

The study involves taking part in an interview. If you consent to be contacted by the research team, we will call you to go through some preliminary questions to make sure you are eligible to take part. If you meet the eligibility criteria, we will arrange a suitable date and time for your interview. If you are not eligible for the study, we will delete any information we have collected. For your convenience, you will be given one of three options for interview: a virtual interview, interview at home, or if you have been recruited from an NHS hospital you will have the option to be interviewed at the hospital. If you do choose to be interviewed at home, it is important that we are able to speak in a quiet, private space.

Interviews are expected to last between 45-90 minutes. You will be asked questions relating to your experience of your relationship prior to and following the diagnosis, about any significant changes you have experienced within your relationship, and what it is about behaviours or personality changes resulting from bvFTD that have directly influenced your experience of your relationship.



### **What are the possible benefits of taking part?**

We hope that taking part will be an opportunity to talk about your experience with someone who is not part of the clinical team or your close family and friends. It may be a cathartic experience and a chance to express yourself. We also hope that the findings from this research will be used to improve the support that spouses and partners of individuals with bvFTD receive. We understand that this can be a complex diagnosis that can have a significant impact on relationships, and we want to understand this in more detail so we can plan helpful support for individuals and families in the future.

### **What are the possible risks of taking part?**

It is not anticipated that there will be any direct risks. However, we will be asking you about a sensitive topic, and the interview may invoke strong emotions. This could be upsetting or feel quite intense. If you become distressed at any point, we can take a break and you will be free to stop the interview at any point without giving a reason. If we are concerned about your wellbeing, we may take the decision to terminate the interview as your wellbeing is our first priority. Contact details for additional support can be found along with this information sheet. We may also signpost you to seek further support.

If we believe that any risk of harm to self or others is disclosed during the course of the interview or during any contact we have with you, we have a duty of care to report this to the relevant party who will follow this up. Local safeguarding procedures will be followed to ensure your safety and the safety of others. In this instance, confidentiality will be breached in order to share the relevant disclosed information. We will discuss this with you however we will not be able to withhold any information disclosed that indicates risk of harm.

### **Do I have to take part?**

No. It is entirely voluntary. If you do agree, we will ask you to sign a consent form prior to being interviewed. If you do not want to take part, this will have no impact on the standard of care your spouse or partner may be receiving from their clinical team.

### **What if there is a problem?**

If you have any concerns regarding the conduct of the research, please see contact details for the research team at the bottom of this sheet. Alternatively, you may wish to contact the following:

- University of Birmingham Research Governance Team:
  - [researchgovernance@contacts.bham.ac.uk](mailto:researchgovernance@contacts.bham.ac.uk)
- [joindementiaresearch.nihr.ac.uk/contactus](http://joindementiaresearch.nihr.ac.uk/contactus)

### **Will my information be kept confidential?**

We will need to use information from you for this research project.



This information will include your name, age, contact details and information from the screening questions and the interview,

People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure. As we are conducting interviews, we will need to use quotes from this to illustrate your experience. We will audio record the interview and create a typed version of your interview and remove any names and places that you may have mentioned. You will be given an alternative name to ensure that any quotes we use will not be identified as coming from you. Your recorded interview will be transferred to a password protected data management system that only the research team will have access to. Once the written version is created, the audio file will be destroyed.

At the end of the interview, your personal details (address, telephone number) will be destroyed however your consent form will be retained. . If you wish to receive a copy of the results, your contact details will also be retained until the end of the research.

The research team will have access to your contact details in order to arrange the interviews. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

### **What will happen if I do not want to continue?**

You can stop being part of the study at any time, without giving a reason. You are free to withdraw at any time prior to and during the interview. If you do change your mind prior to interview, please let the research team know using the contact details below. If at any time during the interview you would like to stop the interview, this is your decision and will be respected. You are under no obligation to continue if you change your mind.

If you change your mind about the inclusion of your interview in the research, you will have up to one week to inform the research team of this decision. This is due to the analysis of your interview beginning soon after the conclusion of your interview.

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

### **Where can you find out more about how your information is used?**

You can find out more about how we use your information at:

- [www.hra.nhs.uk/information-about-patients/](http://www.hra.nhs.uk/information-about-patients/)
- Our leaflet available from [www.hra.nhs.uk/patientdataandresearch](http://www.hra.nhs.uk/patientdataandresearch)
- By asking one of the research team
- By sending an email to [dataprotection@contacts.bham.ac.uk](mailto:dataprotection@contacts.bham.ac.uk)



### **What will happen to the findings from this research?**

The research will be written up and published in an academic journal. It may also be presented at conferences. The final report of the research will possibly include direct quotes from your interview however, any quotes will be fully anonymised. The research will also be presented as part of a Clinical Psychology doctoral thesis.

### **Who is organising and funding this research?**

This research is organised by the University of Birmingham (Centre of Applied Psychology) and supported by local NHS Trusts. It is sponsored by the University of Birmingham who have ensured that the necessary insurance and indemnity arrangements are in place.

### **Who has reviewed and approved this research?**

Any research carried out in the NHS is reviewed by an independent group of people called a Research Ethics Committee (REC) who ensure that all measures to protect participants are in place. This research has been reviewed by the South Yorkshire REC, REC reference 23/YH/0073.

### **What happens next?**

If you would like to take part, please complete the consent to contact form provided with this information sheet if you are being recruited from an NHS site. The research team will then call you to answer any further questions you may have, ask some screening questions, and arrange a time for interview. Please contact Rhea Asfaw if you have any further questions.

*Thank you for considering taking part in this research.*

### **RESEARCH TEAM CONTACT DETAILS**

**Miss Rhea Asfaw** (*Primary Researcher*)

REA619@student.bham.ac.uk

**Dr Stephanie Howarth** (*Research Supervisor – Chief Investigator*)

S.L.Howarth@bham.ac.uk

**Dr Gerard Riley** (*Research Supervisor*)

g.a.riley@bham.ac.uk



## **Useful Contacts and Sources of Support**

Please find below a list of services that may be relevant for you. If at any time during your contact with us, concerns about the immediate safety of yourself or another person are indicated, we will act to manage the risk of harm. This may involve contacting emergency and urgent care services. We would always endeavour to discuss this with you.

### **Carer's support services**

#### **ForwardBirmingham Carers Hub**

The hub offers a wide range of services including information, advice and support to people who care for friends and family with disabilities. Includes free advice on welfare benefits, form filling, 1:1 appointments on request, assistance to help carers to access grants, social services, equipment, finance, care homes, home care, holidays and leisure.

[www.birminghamcarershub.org.uk](http://www.birminghamcarershub.org.uk)

0333 006 9711

#### **Carers Emergency Response Service (CERS)**

CERS is a FREE emergency back-up service to provide support to those caring for a dependent family member, neighbour or friend living in Birmingham. Once registered, a highly trained team member will assess your caring situation and agree an emergency back-up plan. You'll receive a dedicated emergency contact number for times of crisis so CERS can spring into action when you need them most.

Back up care is provided 'at home' for up to two days, allowing alternative arrangements to be made with family, friends, or social services. You can also benefit from a planned sitting service, so you can get to important appointments, such as at the doctors or hospital.

0121 442 2960

#### **Crossroads Care Birmingham, Sandwell, Walsall, and Wolverhampton**

We care about the people we support by providing advice, guidance, and group peer support. In addition, we provide practical respite care so that unpaid carers can take a break from their caring responsibilities, or we provide regular care if the person you care for wishes to remain living in their own home. Staff are highly trained and knowledgeable and provide a quality care service. Crossroads can support you with carer health and wellbeing, support groups / activities, personal care services, respite and carer breaks

0121 553 6483

[www.sandwellcrossroads.org](http://www.sandwellcrossroads.org)



## **Mental health services**

Please contact your GP if you feel you need support with your mental health. Below is a list of some self-referral services.

### **Birmingham Healthy Minds**

Birmingham Healthy Minds is an NHS primary care psychological therapies service. If you are currently experiencing symptoms of low mood, depression and/or anxiety and would like to be able to manage these symptoms better, our service may be able to help you. You can self-refer by calling the number below:

0121 301 2525

### **Black Country Talking Therapies & Healthy Minds Services**

Across the four boroughs, we provide NHS psychological therapy services for people experiencing common mental health problems such as low mood, anxiety, stress, and depression. You can self-refer by calling the appropriate number below:

Sandwell – 0303 033 9903

Dudley – 0800 953 0404

Wolverhampton – 0800 923 0222

Walsall – 0800 953 0995

## **Urgent mental health support**

If there is *immediate, serious risk of harm or injury*, please, contact one of the following:

- 999 or attend your local A&E department
- NHS 111
- Your GP
- Samaritans 116 123
- Birmingham and Solihull Urgent Mental Health Helpline (line managed by MIND) 0121 262 3555 or 0800 915 9292; 24 hours a day, 7 days a week
- Black Country Mental Health Crisis Helpline 0800 008 6516 is (managed by Black Country Healthcare NHS Foundation Trust); 24 hours a day, 7 days a week

## **Dementia/bvFTD specific support**



### **Rare Dementia Support (RDS)**

RDS is a world-leading, UK-based service. We aim to empower, guide and inform people living with a rare dementia diagnosis and those who care about them. Their Direct Support Team provide free information, advice and support. They also run peer support groups throughout the UK.

Telephone: 020 3325 0828



### **Dementia UK / Admiral Nurses**

As dementia specialists, Admiral Nurses help families manage complex needs, considering the person living with dementia and the people around them. When friends and family are worried about a loved one, they give them the confidence to manage their future with dementia. Admiral Nurses help support the people caring for loved ones so that they will have the strength to cope with the bad days, and the energy to enjoy the good days.

Telephone: 0800 888 6678

Email: [helpline@dementiauk.org](mailto:helpline@dementiauk.org)



### **Alzheimer's Society**

Dementia Connect support line for personalised information, support, and advice

Telephone: 0333 150 3456