

Standards of Care

United Kingdom and Ireland

**Psychological Care for Adults,
Children, and Families Affected by
Haemophilia, von Willebrand Disease
& Other Inherited Bleeding Disorders**



HAEM-PSYCH
ASSOCIATION
— UK & IRELAND —

Working with people affected by Inherited Bleeding Disorders

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INTRODUCTION

Psychological care within Inherited Bleeding Disorders can be defined as specialised support aimed at helping both individuals living with haemophilia and other Inherited Bleeding Disorders [hereafter IBDs] and their families, to enhance their mental health and their emotional, psychological and social well-being. Psychological wellbeing is important at every stage of life, from childhood and adolescence through to adulthood and older age and impacts upon our day-to-day functioning, how we relate to others and our quality of life.

As outlined below the HPA recognises that there is a range of service provision throughout the United Kingdom and Ireland and that available resources vary according to each Haemophilia Treatment Centre. Those centres with either the greatest number of severe patients or the least ring-fenced resources may struggle to fulfil all of the following recommendations; however, the principal aim of this document is to move towards equality of psychological care for all patients with IBD's regardless of where they receive their care.

Models of Care

The Haemophilia Psychological Association (HPA) conducted a survey in 2018 to bench-mark the provision of psychological care within Haemophilia Treatment Centres in the UK and Ireland^[1]. The results of this survey indicated that there was neither a uniform model for the provision of psychological care for people living with haemophilia, von Willebrand Disease and other IBDs nor equity of care. In response to these findings the HPA Steering Committee decided in 2019 to draft a Standards of Care Document to assist Haemophilia Treatment Centre's in meeting their patients' psychological needs. The first drafted document was discussed and approved at the HPA's annual general meeting and further ratified by members on 8th September, 2020.

Over the last two decades there has been an increased recognition of the importance of provision of and access to psychological support for people living with long term conditions. For example:

- The national service framework for supporting people with long term conditions states that services need to focus on the empowerment of patients to enable them to access care and support, deal with side effects and treatment, and improve their quality of life^[2]

- NICE guidance for depression in adults with long term conditions makes recommendations on the identification, treatment and management of depression in adults who also have long term physical health conditions (e.g. cardiac disease, diabetes, cancer, or a musculoskeletal or respiratory disorder)^[3,4].

Concurrently, there has been a growing recognition of the psychological needs of patients and families affected by haemophilia and IBDs including:

- The national service specification for people with bleeding disorders^[5,6], states there is a need to be responsive to the lifelong psychosocial needs of patients with hereditary bleeding disorders and their families. It highlights the need for specialist psychological input to meet these complex needs.
- The World Federation of Hemophilia (WFH) Guidelines for the Management of Haemophilia^[7] also recognises the complex psychological burden on IBD patients, carriers, partners and families. The guidelines state that “patients and their families should be provided with psychological and social support” including professional support which is able to both “allow the patient/parents to work through their emotions and to ask questions” and be “able to recognise the warning signs of burnout and depression, which are common with chronic illness, and provide suggestions for coping” (p.23).
- The National public inquiry into the Contaminated Blood episode, established in 2017, has recognised the disparity of access to specialist psychological support and recommended that access to this support is essential for all people infected and affected by the use of infected blood and blood products (Infected Blood Inquiry, 2020)^[8].
- Access to specialised psychological services is now an expected standard of care for UK haemophilia centres^[9].

BACKGROUND

Prevalence of Psychological Difficulties

People with haemophilia (hereafter PwH) or other IBDs, including carriers and their families, have complex and unique psychological needs that merit dedicated, specialist psychological support. At particular life stages and illness transition points PwH or other IBDs may experience increased psychological, as well as physiological challenges and difficulties, for example:

- At diagnosis of an IBD
- Parents learning to infuse their child at home

- Developing an inhibitor shortly after starting clotting factor treatment
- Starting nursery or school
- Young person learning to self-infuse independently
- Moving to secondary school
- Adolescence
- Onset of sexual maturation (e.g. menstruation)
- Carrier genetic-testing and diagnosis
- Young person's self-management and treatment of their condition, including transitioning from paediatric to adult services
- Leaving home for further education or work
- Disclosure at work
- Disclosing their diagnosis (IBD or carrier-ship) to a potential partner
- Thinking about having a family e.g. genetic testing, reproductive options and delivery
- Living with co-infections such as HIV and Hepatitis
- Living with the burden of musculoskeletal damage and its impact on life choices and activity
- Pain management; supporting patients who live with persistent pain e.g. associated with arthropathy
- Changing/switching treatment products and regimes
- Emerging availability of gene therapy
- Ageing and later life including coping with co-morbidities
- The onset of Acquired Haemophilia, often in the later years

Research suggests that both adults and children living with a chronic condition are 2-3 times more likely to experience emotional and behavioural difficulties compared with those without a chronic condition^[10,11]. Anxiety and depression occur in up to 32% and 37% of PwH respectively^[12,13]. There is also evidence that patients with chronic conditions and their families can experience significant trauma due to treatments and experiences related to their condition^[14]. Quality of life is reduced particularly in more severe disease^[15]. The impact of a carrier diagnosis has also been reported as being perceived as 'negative' by 48% of potential carriers^[16]. There is good evidence that people with long-term conditions and mental health needs are less likely to be in employment than those with physical illness alone, and the productivity of those in employment is reduced^[17].

Impact on Clinical Management and Patient Care

Psychological problems can complicate the care and clinical management of people with IBDs through reduced self-efficacy and self-confidence, missed clinic appointments, increased emergency attendance and engagement in risky behaviours including alcohol, drug use and smoking as coping strategies. Psychological issues can further impact upon an individual's adherence to treatment plans and their capacity to accept support from their MDT. Adherence to demanding and complex treatments as well as the recording of bleeds and use of clotting factor treatment in

haemophilia can be challenging for PwH and other IBDs. Reported levels of adherence to prophylaxis vary widely from 17%^[18] to 59%^[19].

The Experience of Co-infections

The transmission of viral infections (HIV, hepatitis B and C) through contaminated blood products has had a profound impact on the haemophilia community. Patients and families affected by HIV and hepatitis infection experience particularly complex medical and psychosocial needs and decreased quality of life^[20]. Within the haemophilia community there continue to be concerns about the theoretical transmission of other agents, including variant Creutzfeldt–Jakob disease (vCJD) . Infectious agent transmission makes the delivery of clinical care a particularly sensitive and important issue for all patients and their families. The announcement by the British Government in July 2017 for a National Public Inquiry into the Contaminated Blood episode has re-ignited complex trauma reactions which undermine adjustment and adaptation for those individuals who received contaminated blood as well as for their families. Inquiry testimonies from both those infected and affected and from the psychosocial expert group highlighted a range of negative outcomes, including anxiety, depression, anger, post-traumatic stress (PTSD), grief and a loss of trust in the Healthcare system^[21].

Women and Inherited Bleeding Disorders

Women are affected by a number of bleeding disorders including von Willebrand disease (vWD), which affects up to 1% of the population, as well as other rare bleeding disorders^[22,23]. However, females with the gene for haemophilia A or B can also manifest bleeding symptoms, and a significant number of these females have clotting factor levels that would classify them as having mild, moderate and even on occasion severe haemophilia^[24].

Females with bleeding disorders will require the same management as males when faced with haemostatic challenges such as surgery, epistaxis, joint and muscle bleeds; whereas menstruation, pregnancy and childbirth are additional bleeding challenges unique to women with bleeding disorders^[24].

In addition to dealing with the clinical manifestations of bleeding in women with IBD, an important aspect of care is recognising and addressing the psychological impact of their condition. Women have reported feelings of guilt, self-blame, sadness and/or grief at being labelled as the parent who is responsible for passing a genetic condition onto their children ^[25]. Women have further described the challenges to their own life when living with a symptomatic bleeding condition, such as increased absences from school or work, social embarrassment and self-consciousness^[26].

The Changing Treatment Landscape

The treatment of haemophilia is currently, and may well continue to be, on the cusp of significant developments. It is likely that there will be many benefits for PwH and other IBDs but the changes may also be very psychologically challenging for patients who have spent a life-time with a chronic condition. Psychologists, psychotherapists and others responsible for psychological care have a vital role to play in supporting PwH and IBDs through their decision-making process and any subsequent implementation of the new treatments.

Parity Between Physical and Mental Health Resources

Parity of esteem is the principle by which mental health must be given equal priority to physical health. It was enshrined in law in the United Kingdom by the Health and Social Care Act 2012^[27] and individually there is a consensus on this matter in England, Scotland^[28], Wales and Ireland^[29].

In addition, it is recognised that people with long term physical illnesses suffer more complications if they also develop mental health problems, increasing the cost of care by an average of 45%^[30]. There is good evidence that dedicated mental health provision as part of an integrated service can substantially reduce these poorer outcomes. For example, in the case of Type 2 diabetes, £1.8 billion of additional costs can be attributed to poor mental health, yet fewer than 15% of people with diabetes have access to psychological support^[30]. Pilot schemes show providing such support improves health and cuts costs by 25%^[30].

STANDARDS OF CARE

In 2019 the HPA steering committee drafted a Standards of Care document to assist Haemophilia Treatment Centres in meeting their patients' psychological needs. The following set of standards were agreed, to reflect the levels of psychological support that should be available to all PwH and IBDs (and, where appropriate, their families/carers) across treatment centres.

STANDARD 1 – Psychological Provision

A tiered model adapted from the NICE guidance for palliative care services^[31] recommends four levels of psychological assessment and intervention that should be offered by different professionals across services (Appendix A). Our adapted model outlines four similar levels of psychological support that should be developed and implemented within treatment centres (Appendix B). Levels 1 and 2 should, in the first instance, be provided by all health and social care professionals directly responsible for PwH and other IBDs. More severe psychological distress should be managed at levels 3 and 4 by fully trained and accredited psychological specialists,

including clinical psychologists, psychotherapists, counsellors and liaison psychiatrists (see Appendices A and B for further detail).

Level One and Two: Awareness and General Psychological Support

- All PwH and IBDs should be provided with psychological support that includes information, signposting and supportive communication. These functions should be carried out by all members of the Multi-Disciplinary Team (MDT) and include recognition of psychological needs, active listening, effective information giving, compassionate communication and general psychological support with appropriate supervision.

Level Three and Four: Specialist Psychological Support and Intervention

- Patients (and, where appropriate, their families/carers) should also be provided, according to agreed referral criteria, with more specialist assessment and intervention when indicated through psychological screening and assessment. Interventions may draw upon a range of psychological models (e.g. Cognitive Behavioural Therapy, Acceptance and Commitment Therapy, Cognitive Analytic Therapy and Systemic Family Therapy) and will be evidence-based with clinicians referring to NICE and SIGN guidance to meet the needs and difficulties of individual patients.
- These interventions should be supplied by a fully trained and accredited applied psychologist, practising psychotherapist or counsellor with specialist knowledge of haemophilia and IBDs, or with transferrable skills working with different chronic conditions within the NHS or other Health settings.
- The psychological professional should be a member of the Haemophilia Psychological Association (HPA) and be able to attend / undertake training to ensure the continuation of best practice and provision of quality care.
- The psychological professional should have dedicated and protected hours including flexibility within these hours to manage their haemophilia caseload and service provision.
- Mental health specialists working at level 4 provide specialist psychological and psychiatric interventions e.g. psychotherapy and cognitive behavioural therapy (CBT).

STANDARD 2 – Referrals and Assessment

A clear referral pathway should be established allowing members of the MDT to refer to the relevant psychological professional.

Patients referred for psychological input should be seen within the appropriate time frame according to assessed need. However due to the long distances that some patients travel, the patient may be offered a remote (online/telephone) appointment or be referred to local services within the community as deemed clinically appropriate.

High Priority Referrals

- A patient should be reviewed as soon as is clinically possible, normally within 3 weeks^[9]. This could be a telephone triage or face to face review.

Routine Referrals

- A patient should be offered an appointment which will be within 6-8 weeks.

Acute Psychological Emergencies

- A psychological emergency is where screening or clinical observation identifies a serious and immediate risk of harm of the patient to self or others.
- It needs to be recognised that haemophilia centres do not operate emergency psychological services and therefore are unable to respond to urgent risk or crisis. Referrers should follow their local risk management, suicide and safeguarding policies, which should include adult and child patients being directed to the appropriate services in a timely manner e.g. the Hospital Liaison Psychiatry Team, an Accident and Emergency Department or through an urgent referral to CAMHS.

STANDARD 3 – Clinical Management: Competence to provide psychological support

Psychological professionals working with PwH and IBDs should provide the highest evidence-based standards of clinical care.

- PwH and IBDs should have their psychological support provided by competent practitioners who have been appropriately trained and have demonstrated the necessary competencies in accordance with their professional body (see membership section of HPA constitution^[32]).
- Clinical care should be consistent with the standards documented by the British Psychological Society (BPS), United Kingdom Committee on Psychotherapy (UKCP), Psychological Society of Ireland (PSI) or British Association for Counselling and Psychotherapy (BACP) and in line with the standards of conduct, performance and ethics set out by the Health Care

Professions Council (HCPC)^[33] or CORU (the Independent regulator for health and social care professionals in Ireland).

- Services providing psychological support for PwH and IBDs should ensure that their practitioners can demonstrate competence on an ongoing basis and should make provision to support the maintenance of competence through training, continuous professional development (CPD) and clinical supervision.
- Psychological professionals should contribute to the development and articulation of best practice by exercising the skills of a reflexive and reflective psychological professional, taking part in regular professional supervision and maintaining an active engagement with current developments in the professional fields of applied psychology, psychotherapy or counselling as appropriate.

STANDARD 4 – Multidisciplinary Review and/or communication with the MDT

- As stated within the National Service Specification, all PwH and other IBDs should be offered a regular clinical multidisciplinary review^[2,3].
- PwH and other IBDs should be given the opportunity to discuss their psychological wellbeing with the professionals providing their health and social care as a part of standard patient care.
- PwH and other IBDs should have access to screening for the presence of psychological difficulties (either by a validated instrument or through clinical interview) on an on-going basis and additional screening pathways should be in place for those who need them. The way in which this service is delivered may differ between services – e.g. screening by a psychological professional versus a screening tool used by other members of the MDT.
- PwH and other IBDs whose screening suggests significant difficulties, which would warrant further specialist input should be offered a referral to an appropriate service or community agency (e.g. community mental health team, drug and alcohol services) where their needs will be more appropriately met.
- Psychological care should form part of a multidisciplinary review of the patient, with relevant information being shared amongst the MDT and other healthcare professionals as appropriate.
- The co-location of the psychological professional within the haemophilia team enables the normalisation of the consideration of psychological factors for both staff and patients and maximises opportunities for consultation, support and joint working.

- Good communication with the MDT should be maintained through attendance at relevant MDT meetings.
- Psychological professionals should offer consultation to members of the MDT, drawing upon psychological theory and practice to enhance the understanding, treatment and psychological approach to patient difficulties. This may include but is not limited to cases where the psychological professional may not be working directly with a PwH or other IBD.

STANDARD 5 – Education and Supervision

Specialist applied psychologists, practising psychotherapists and counsellors should provide the following services:

- Education on the psychological factors that impact PwH and other IBDs and the role of psychological services within the medical team in the management of haemophilia.
- Training, supervision and CPD for other members of the MDT offering psychological support at levels one and two to PwH and other IBDs. For example, identification of psychological needs, active listening, compassionate communication and general psychological support (see Appendices A and B).

STANDARD 6 – Life-Stages, Transitions and Family/Carer Support

Psychological care should be available to support patients and when appropriate their families/carers through different IBD life stages and transitions (see Appendix C).

- Appropriate developmental or cohort sensitive interventions/support should be offered across the whole life-span, including children, adolescence and puberty, adult and later years.
- This will include promotion of independent management of the individual's condition within school, further education, career, adult life and later years.
- The psychological professional should be actively involved in assisting in the transfer of haemophilia care from the paediatric to an adult-setting as appropriate.
- Psychological assessment and support should be available to help understand and support the unique needs of carriers and women with IBDs.

- Pregnancy counselling should be offered to carriers of haemophilia to discuss suitable reproductive options and methods of prenatal diagnosis and pregnancy management.
- Psychological input to foster supportive relationships and clear communication within families.
- It is recognised that, with the ageing population, the current generation of PwH and other IBDs are living longer, creating greater potential for issues with mobility, cognitive deterioration, coronary comorbidities and isolation. Appropriate attention should be given to the specialist needs of this patient group.

STANDARD 7 – Participation in CPD, Service Evaluations, Research and Audit

- Psychological professionals should engage in CPD specific to haemophilia and IBDs. Attendance at specialised IBD national and international meetings facilitates individual and service development from both a psychological and an MDT perspective.
- Specialist psychological care activity should be monitored and audited as required.
- Effectiveness of psychological care should be evaluated through routine use of appropriate outcome measures.
- PwH and other IBDs should be provided with opportunities for feedback on psychological support services as part of service evaluation, to inform service management, local policy and quality improvement.
- Psychological professionals should contribute to general service evaluation, audit and research projects, as well as seeking to conduct their own research into the field of IBDs where appropriate.

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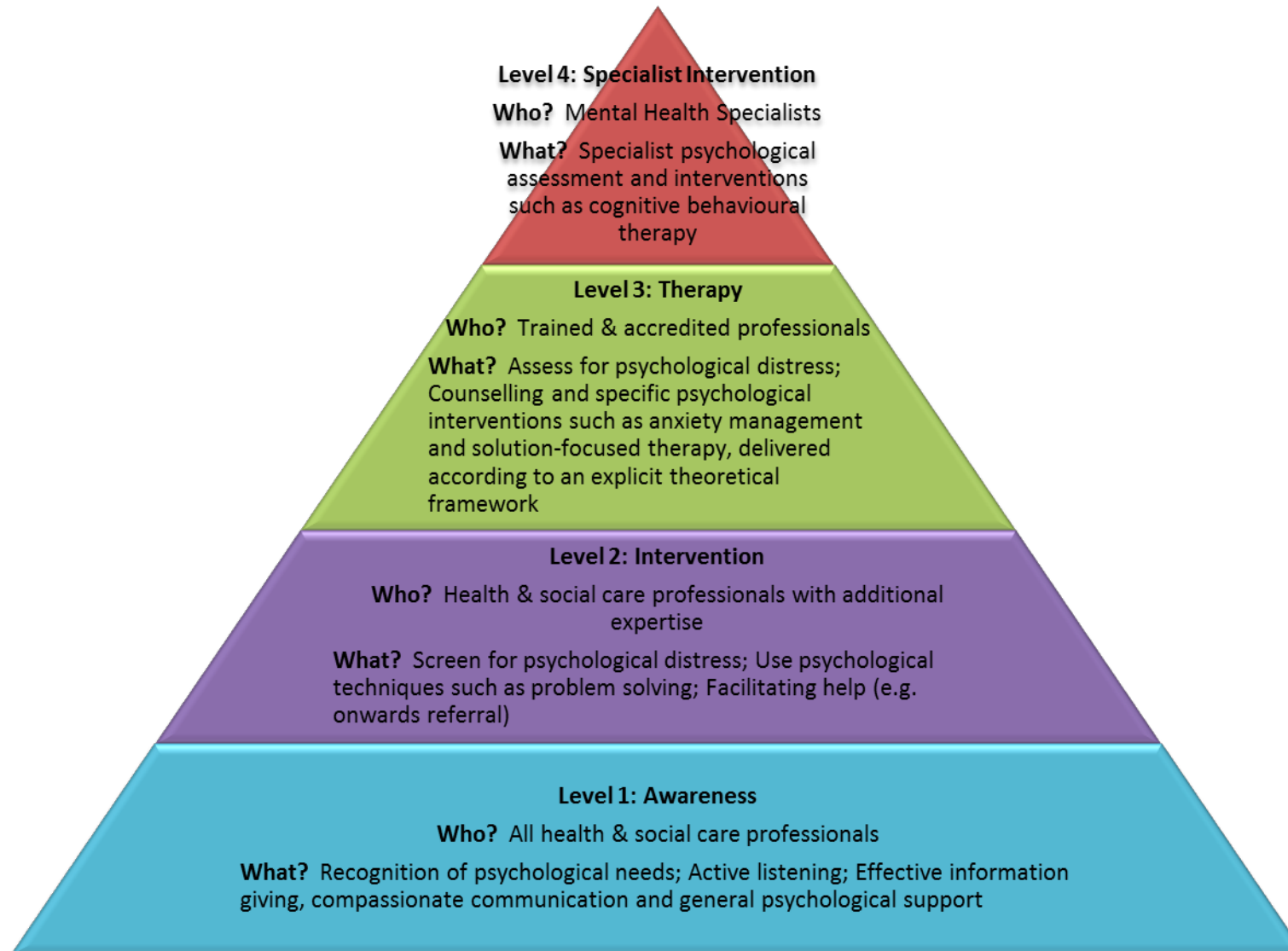
Nicola Dunn, Chairperson
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Frances Wilkins, Secretary

Appendix A: Recommended model of professional psychological assessment and support^[34]



Level	Group	Assessment	Intervention
1	All health and social care professionals	Recognition of psychological needs	Effective information giving, compassionate communication and general psychological support
2	Health and social care professionals with additional expertise	Screening for psychological distress	Psychological techniques such as problem solving
3	Trained and accredited professionals	Assessed for psychological distress and diagnosis of some psychopathology	Couselling and specific psychological interventions such as anxiety management and solution-focused therapy, delivered according to an explicit theoretical framework
4	Mental health specialists	Diagnosis of psychopathology	Specialist psychological and psychiatric interventions such as psychotherapy, including cognitive behavioural therapy (CBT)

Appendix B: A four-tiered model of psychological support, adapted from NICE guidance for psychological support in palliative care



Appendix C: Model demonstrating empowerment through transition through life stages for PwH [35]

