Batten Disease Family Association Safeguarding Policy

The Batten Disease Family Association (BDFA) exists in order that no family should walk the path of Batten Disease alone.

Our primary commitment is to ensure that every child, young person and adult is enabled to live their life fully and to their maximum potential (for related child and adult safeguarding procedures refer to Appendix 2 and Appendix 3).

- We are a centre of excellence and the national patient organisation for the UK.
- We work holistically with the whole family, understanding the complex impact of Batten Disease on every family member.
- We advocate and dynamically challenge individual practitioners and multi-disciplinary teams across health, education and social care.

Our work is underpinned by 5 strategic pillars:

- Elevating standard of care
- Raising awareness
- Supporting research
- Building the organisation
- Advocacy

Fundamental to our person-centred ways of working are:

- Being professionally caring and kind
- Being trustworthy and reliable
- Being empathic and receptive
- Being an active listener and deeply respectful

The life-lived dimension of our work is a driving force in our work with families; they work closely with us, thus reflecting our 'family association' in a meaningful way.

Governance and Management

Our Board of Trustees owns its accountability for safeguarding with regards to:

- The staff team

- The children, young people, adults and families we serve

Their commitment is demonstrated by the allocation of time, finances and resources. This ensures that safeguarding is both current and meaningful.

The named Trustee for safeguarding is **Chair of Trustees**

The **Chief Executive Officer (CEO),** is the DESIGNATED SAFEGUARDING LEAD (DSL) for safeguarding for the BDFA at a strategic level. She works closely with the Board of Trustees to ensure that the strategic vision is translated into effective day-to-day practice.

Safeguarding at an Operational Level

The **Head of Support and Advocacy is the DESIGNATED SAFEGUARDING LEAD at an operational level (operational DSL) with deputies Head of Scientific Affairs or CEO**.

All members of our Designated Safeguarding Team attend professional training at Level 3 (Children) and Level 2 (Adults), to equip them to fulfil this role. Professional learning and development are updated at regular two-yearly intervals, in step with standards across the wider Children's Service workforce.

In addition, the operational DSL calls upon support, advice and expertise outside of BDFA, as and when required.

How Safeguarding is embedded in our work

Our duty of care includes recognising the interface between family support and advocacy on behalf of the child, young person or adult. This includes using our professional expertise in noting a marked change in the health and well-being of the individual.

We own our responsibility to guard against families becoming over-dependent on us.

Often the first indicator of a safeguarding concern arises through parental ill health or a direct disclosure made by that parent and/or family member.

We recognise our safeguarding responsibilities across a number of areas of work at an organisational level.

<u>Safer Recruitment and Selection</u>

The Safer Recruitment and Selection Consortium guidance is embedded in our practice in regards to manager, practitioner and volunteers. Equally, all family-facing managers, practitioners and peer befrienders are subject to Disclosure and Barring Service (DBS) enhanced checks.

Induction and CPD

The induction of team members is a stepped process within the first months of employment including level two training in safeguarding and thorough introduction to all BDFA policies. We allocate a training day per year for all staff members with the aim of building on prior knowledge and developing professional practice.

How we communicate our safeguarding role to families

We routinely talk to families about our safeguarding role from the beginning of our professional relationship and at regular intervals. We also take time to explain how professionals might misuse their professional position of trust within families including an abuse of professional power.

Information sharing and confidentiality

We encourage a professional and rigorous approach to the sharing of information. We understand the difference between information sharing and confidentiality and bring discipline to implementing this in day-to-day practice.

Recording

We have a comprehensive recording system to note our interactions with all families and professional services.

In addition, we record our interactions on family work on a secure database, with restricted access to key managers. We have a secure area for safeguarding concerns and record individual incidents, which may or may not go on to meet the threshold for a safeguarding referral.

Lone Working

The BDFA Lone Working Policy specifies practitioners' responsibility to conduct a risk assessment at the first visit and periodically thereafter, in consultation with their manager. When contacts are on zoom, attention should be given to what can be seen, heard and 'sensed' and not, as opposed to assuming that the interaction is a reflection of what may be occurring in the household. For detail guidance related to lone working refer to the BDFA Lone Working Policy.

Supervision

The BDFA has a structured supervision policy that provides the opportunity for reflection on practice, a focus on professional development, including key elements of the professional role. In addition, key senior staff receive clinical supervision.

Keeping our safeguarding approach current

We pride ourselves on keeping abreast with modern safeguarding practice, regularly scanning for developmental trends, strengths-oriented models and evidence-based approaches. We do this through:

- Ensuring that safeguarding is a standard agenda item on the quarterly Board of Trustee meetings and the monthly staff team meeting.
- Initiating interprofessional discussions with our national and regional partners including Great Ormond Street Hospital (GOSH) and key consultants in Batten disease.
- Innovating in the area of interprofessional understanding of a complex and unpredictable disease, to instil a meaningful understanding of change for families.

Volunteering

We recruit volunteers to a high standard and provide regular supervision and support. We acknowledge the lived experience of many of our volunteers, by drawing on their strengths and individual family journeys and assisting in establishing effective professional boundaries. We do this through ongoing contact within our Batten staff team, attendance on our training programme and regular support by our Peer Befriending Coordinator where appropriate.

This policy is subject to periodic reviews. The policy will be updated and new version issued in case there is new information, law or guidance.

Appendix 1

Batten Disease Family Association Child Protection Procedure

All of the children and young people we work with at BDFA are recognised as 'Children in Need'. This means a specialist team of professionals and family members should support the family, using a 'Team around the Family' approach.

On occasions though, our concerns are much greater. You might notice :

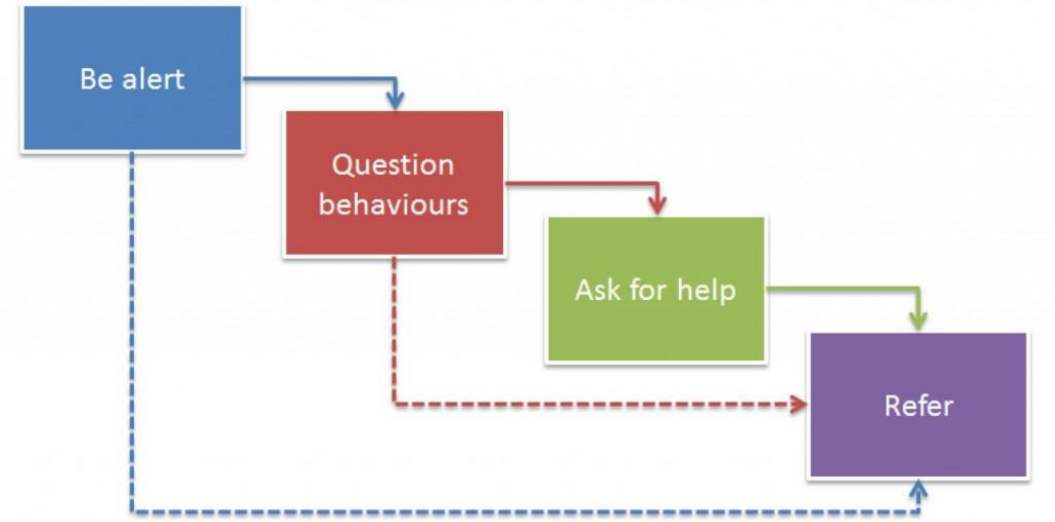
- a deterioration in physical care, or injuries, rough handling, excessive medication
- breakdown in family relationship, disputes and emotional abuse and/or neglect
- behaviours that seem to be expressing unhappiness, distress and/or disagreement about treatment options
- a witnessed assault, or abusive act or series of acts
- a direct disclosure by the child, parent and/or family member

Dementia and altered states of consciousness

The onset of dementia (altered states of consciousness) for children with Batten disease can be unpredictable. Staff members, Trustees and/or Volunteers should be mindful that children may not be able to communicate their concerns, or may not be aware of what they are experiencing. There may be a very sudden need to respond and bring a deep level of understanding, just at the point that the child with Batten disease and their family are feeling distressed and confused. It is therefore essential to be sensitive, responsive and tune in carefully to what is being said. In these kinds of situations, things appear to have reached a Child Protection level of concern.

This procedure lays out the practical steps to be followed when a BDFA Member of Staff or Member of the Board of Trustees and/or Volunteer believes a child, under 18 years, is being harmed at this level.

Steps for Assessment of Harm



Be Alert

It is the responsibility of all staff, board members and volunteers to be well-informed and vigilant to the welfare, safety and protection of all of those in our care.

Question Behaviours

In the course of contact with families, they naturally talk about day to day life. Staff, board members and volunteers are responsible for entering into discussion in a responsive way regarding concerns. Care should be taken to ensure these inquiries are made, using open-ended questions.

In all situations you should approach the child, young person and/or parent in a kindly, warm way. For example :

"Oh, what happened to your arm ?" ; "How are you as a family at the moment ?"(You seem distressed, or the young person seems agitated)

Listen carefully and then perhaps ask supplementary questions. Be mindful not to use leading questions.

If you remain concerned, then tell the person that you are concerned and why.

Explain that you need to talk to your operational DSL.

Make a written record of your observations and discussions, using the Record of Concern Form (Appendix 4).

Ask for Help

Approach your operational DSL for the BDFA. You and your operational DSL will have a conversation regarding the child and family, based on the dimensions on this Assessment Framework Triangle for Children in Need and their Families.

In discussion together it will become clear if this concern is at a level that it needs to be referred to the MASH (Multi Agency Safeguarding Hub) in the child's Local Authority. This decision is the responsibility of the operational DSL.

In your operational DSL absence, contact their deputies.

Responding to a Disclosure

All children, young people and parents think carefully about who they talk to. If they begin to make a disclosure it is important to recognise that this is unusual and that they have invested a level of trust in you. Therefore, tune in and listen carefully.

Find an appropriate early opportunity to explain that you will need to share what you have been told with the operational DSL.

Allow the child, young person and/or parent to continue at their own pace and ask open-ended questions for clarification only.

Only talk with the child, young person and/or parent for as long as they are prepared to talk and to establish what they are telling you.

Complete the Record of Concern form (Appendix 4), as you would for any other safeguarding concern.

Appendix 2

Batten Disease Family Association Adult at Risk Procedure

All Adults living with Batten Disease should be subject to Care and Support Needs under the Care Act**.** We have a duty to promote the core principles of the Act, which are :

Empowerment – Prevention – Proportionality – Protection – Partnership and Accountability. Please refer to additional information in Appendix 3.

This means that decisions should be made in partnership with the adult at risk, unless they lack mental capacity.

As the course of the disease progresses, it is essential that balance is brought to :

The Adult at Risk's right to determine their own life choices, having regard to their views, wishes, feelings and beliefs and providing meaningful support to the family and/or carers, who are meeting significant dilemmas and challenges daily.

When circumstances have reached a 'protection' level

All adults within our care should be able to live free from fear and harm, but some may find it hard to get the help and support they need, for a number of reasons. This is generally the stage at which the Adult at Risk's needs 'may' reach the 'protection' level.

If there are indications that the Adult at Risk is fearful and/or being harmed, this would be the stage at which that Adult's needs meet the protection threshold.

Examples of a protection level of concern might include :
- -

- **deterioration in care for the adult, suggestion of physical injury, over or under medicating**
- **a breakdown in family ability to care for the adult physically or emotionally, including disputes in medical intervention and/or end of life care choices**
- **beyond a usual level of emotional distress**
- **physically challenging behaviours which result in unnecessary restraint and/or incidents of assault**
- **a direct disclosure of abuse**

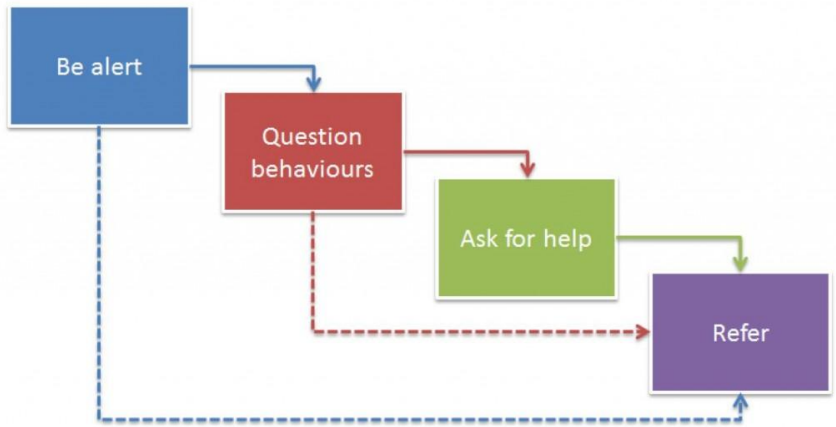
- **a family member or care giver using language or, acting in a way that causes you concern**

Dementia and altered states of consciousness

The onset of dementia (altered states of consciousness) for adults with Batten's Disease can be unpredictable. There may be a very sudden need to respond and bring a deep level of understanding, just at the point that the Adult with Batten's Disease and their family are feeling distressed and confused. It is therefore essential to be sensitive, responsive and tune in carefully to what is being said.

This procedure lays out the practical steps to be followed when a BDFA Member of Staff or Member of the Board of Trustees and/or Volunteer believes an adult, over 18 years, is being harmed or abused at this level. This includes a situation where a family member has reached a crisis point in their capacity to care.

<u>Steps for Assessment of Harm</u>



Be Alert

It is the responsibility of all staff, board members and volunteers to be well-informed and vigilant to the welfare, safety and protection of all of those in our care. When working with Adults at Risk it is essential that we are able to incorporate the principles of the Care Act and Mental Capacity Act. These principles are included in the appendices to this document.

Question Behaviours

In the course of contact with families, they naturally talk about day to day life. Staff, board members and volunteers are responsible for entering into discussion in a responsive way regarding concerns. Care should be taken to ensure these inquiries are made, using open-ended questions

and perhaps talking to the Adult at Risk and family member/carer separately. **If you believe that talking to a family member or carer may place the Adult at Risk of further harm, trust your judgement and take your concerns direct to your operational DSL.**

In all situations you should approach the Adult at Risk and/or family member or care giver in a kindly, warm way. For example :

"Oh, what happened to your arm ?" ; "How are you as a family at the moment ?" (You seem distressed, or Adult at Risk seems more agitated than usual)

"You've been managing really well, but it seems like things have become too difficult now".

Listen carefully and then perhaps ask supplementary questions. Be mindful not to use leading questions.

Be aware of how **'able'** the Adult at Risk appears in expressing their views. For example, might they express their views more freely if you talk to them alone ? Does their capacity appear impaired ? If you remain concerned, then tell them that you are concerned and why.

Explain that you need to talk to your operational DSL for Safeguarding.

NB. You do not need to get the agreement or 'permission' of the family member or carer to approach your operational DSL.

Make a written record of your observations and discussions, using the Record of Concern Form.

Ask for Help

Approach your operational DSL. You and your operational DSL will have a conversation regarding the Adult at Risk, their family and/or carer, based on the dimensions on this Assessment Framework Triangle.

Although the Assessment Framework is used primarily in child safeguarding it is a useful guide for thinking about the needs of adults in our care, whilst not treating them as a child.

In discussion together it will become clear if this concern is at a level that it needs to be referred to Adult Social Care in the Adult at Risk's Local Authority. This decision is the responsibility of the operational DSL. In their absence, contact their deputies.

Responding to a Disclosure

All Adults at Risk, family members and care givers think carefully about who they talk to. If they begin to make a disclosure it is important to recognise that this is unusual and that they have invested a level of trust in you. It is important to tune in and listen carefully.

Find an appropriate early opportunity to explain that you will need to share what you have been told with the operational DSL.

If it is the Adult at Risk making a disclosure, encourage them to continue at their own pace, mindful of their Mental Capacity.

Consider whether the adult may lack capacity to make decisions about their own or other people's safety and wellbeing. If you and the operational DSL in consultation believe it is in their best interest to act against their wishes, or, without their consent you must record your decision and the reasons for this.

Complete the Record of Concern form (Appendix 4), as you would for any other safeguarding concern.

Breakdown in the family unit
It is essential that we pay very close attention to possible break-down in the family dynamic. This might include :

- Drug or alcohol use at a worrying level
- A crisis in care
- Mental health needs become evident, or deteriorate
- A parent or family member makes a direct disclosure, including reference to coercive control and/or domestic abuse

It is vitally important that we tune in, listen and respond in exactly the same way as we would if we were speaking with the Adult at Risk (who is living with Batten's Disease).
Take these concerns to the operational DSL, as you would with any protection matter

Complaints regarding quality of care and/or abuse by Professionals

If an Adult at Risk or family member;

- indicates that they are unhappy with a level of care ,
- believe that abuse or neglect has occurred and/or
- appear to be controlled or manipulated in a care setting

it is important to encourage this disclosure and to carefully follow the procedure for Allegations against Professionals who Abuse their Positions of Trust. This often includes a referral to the Care Quality Commission.

Appendix 3

6 Key Principles for Practice in Safeguarding Vulnerable Adults

Empowerment – People being supported and encouraged to make their own decisions and informed consent

Prevention – It is better to take action before harm occurs.

Proportionality – The least intrusive response appropriate to the risk presented.

Protection – Support and representation for those in greatest need.

Partnership – Local solutions through services working with their communities. Communities have a part to play in preventing, detecting and reporting neglect and abuse.

Accountability – Accountability and transparency in safeguarding practice.

Five Statutory Principles

The Act is underpinned by five principles, which are contained within the act and explained in the Mental Capacity Act code of practice:

- a presumption of capacity – every adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless it is proved otherwise
- the right for individuals to be supported to make their own decisions – people must be given all appropriate help before anyone concludes that they cannot make their own decisions
- that individuals must retain the right to make what might be seen as eccentric or unwise decisions
- best interests – anything done for or on behalf of people without capacity must be in their best interests
- least restrictive intervention – anything done for or on behalf of people without capacity should be an option that is less restrictive of their basic needs – as long as it is still in their best interests.

Appendix 4 **Record of concern form**

Date/ Time	Name of vulnerable Child / Adult	Nature of Concern	Completed By – Staff name/role
Section below to be completed by the operational DSL			
Date/ Time	Notes from DSL /staff member discussion		Name of DSL
Safeguarding concern upheld	If yes has family been informed Yes/No and detail	Notes from discussion with (tick as appropriate) LADO (Local Authority Designated Officer) MASH Team	DSL sign/date
Yes / No		Name of officer reporting to:	
		Detail of discussion	
Follow Up from LADO/MASH			
Date/ time	Outcome		DSL sign/date

Policy Ownership

Policy Name	Version	Date
BDFA Safeguarding Policy	V4.0	17 September 2026

Reviewers

Name	Position
Liz Brownnutt	Chief Executive Officer
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Nigel Nicholls	Chair of Trustees

Document Approved by

BDFA Chair of the Board of Trustees

Nigel Nicholls

Nigel Nicholls

Date: 17th September 2026