



Policy – Making a referral to the DEBRA EB Community Support team

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DEBRA is the national charity that supports individuals and families affected by Epidermolysis Bullosa (EB) – a painful genetic skin blistering condition.

For more information and support please visit www.debra.org.uk or call 01344 771961.

A charity registered in England and Wales (1084958) and Scotland (SC039654).

Policy – Making a referral to the DEBRA Community Support Team

1. Making a Referral to the DEBRA EB Community Support Team

This document outlines how to make a referral to the DEBRA EB Community Support Team.

2. Policy statement

DEBRA is committed to providing a free, fair and accessible EB Community Support service which is open to anyone living or working with EB across the UK.

3. Purpose

To provide a clear and straight forward process for accessing DEBRA's EB Community Support services for people living with EB, other charities and health and social care professionals.

4. Scope

This policy applies to all staff working within DEBRA, specifically the EB Community Support team. Information within the policy will support and inform other professionals and members of the EB community in making a referral to the service.

5. Objective

DEBRA aims to provide an EB Community Support service which operates to the highest standards, giving an efficient, effective and confidential service. Our aim is to make access to the service easy and transparent.

6. Policy details

6.1 The DEBRA EB Community Support team

The DEBRA EB Community Support Managers work with individuals and families, providing information, advocacy and support services for issues such as benefits, finance, housing, education and employment. The team has knowledge and experience of working with people living with EB. They know how particular issues of EB may affect family life, someone's functioning, housing, work and leisure needs. Crucially, the team are experienced in communicating these things to other agencies.

The team work alongside specialist EB nurses and other health and social care professionals to ensure people with EB get the support they need. While no member of the team is employed as a qualified nurse, social worker, financial advisor or specialist benefits expert, the team have a wealth of knowledge and experience in health and social care practice.

The DEBRA EB Community Support service is not intended to replicate or take over the responsibility of statutory agencies. It is designed to work in partnership with people living with EB and to support them when communicating with statutory agencies and health and social care services.

6.2 DEBRA EB Community Support service

The EB Community Support team provides many different support services which are aimed at meeting the needs of the EB community. These include:

- information about a range of issues relating to living with EB
- help with benefits
- representation at tribunals and appeals
- one-to-one support

- advocacy
- assistance with emergency funding
- affordable breaks in the DEBRA holiday homes
- befriending – someone outside the family circle to talk to

6.3 Eligibility to access the service

The DEBRA EB Community Support service is free and accessible to any member of the EB community.

Each case will be treated strictly on its merits and all clients will receive equal and fair treatment within a transparent process taking full account of DEBRA's vision and purpose. Each case will be considered in the context of our statutory responsibilities under all relevant legislation, such as:

- Human Rights Act 1998
- Data Protection Act 1998
- Equality Act 2010
- Safeguarding Vulnerable Groups Act 2006
- The Care Act 2014
- Health and Social Care (Safety and Quality) Act 2015

6.4 Data Protection

The EB Community Support team will ask for consent to include the client's details on the EB Community Support team database. DEBRA fully complies with the Data Protection Act 1998. Please refer to the DEBRA Data Protection policy.

Prior to recording or sharing information the client's consent must be obtained. It is DEBRA's practice to ask clients for their consent to access the service: this includes consent for record keeping and sharing of specific information.

Details of the services provided by the EB Community Support team are available in DEBRA information leaflets and the DEBRA website (www.debra.org.uk).

6.5 Links to other DEBRA policies, documents and procedures include:

- DEBRA Employee's Handbook – confidentiality, record keeping
- Record Keeping Policy and procedure and auditing
- DEBRA Complaints Policy

7. Documentation and records

7.1 Consent for record keeping and access to the EB Community Support Service

All clients or representatives will be given information about the service. They will be asked to consent to access the service and ongoing recording of activity and information. This can be:

- verbal: consent may be given initially and then recorded in client's notes
- in writing
- by text
- by email

7.2 Consent

If the person making the referral is not the person with EB, consent to make the referral must be obtained from the person with EB, the parent, guardian or representative.

If the person making the referral contacts the Membership team, only brief contact details will be taken (name, address, telephone number, general reason for referral) and the referral will be sent to the appropriate EB Community Support Manager to complete the process.

If a health or social care professional / practitioner makes the initial referral, it is their responsibility to obtain consent from the client or the client's representative to share the client's personal information.

All referrals and confirmation of consent will be recorded on the community support database. The community support activity records will remain confidential to the DEBRA EB Community Support team and the DEBRA Membership team.

Clients may request a copy of their record. This request must be made in writing.

The referrals process, recording of data, and client satisfaction will be audited, to monitor and maintain good standards of record keeping and compliance with current legislation.

8. Roles and responsibilities

All referrals must be recorded and prioritised according to the needs of the person requiring support.

The priority will be evaluated by the EB Community Support Manager receiving the referral.

Regional EB Community Support Managers will regularly review referrals and area caseloads.

9. Referral procedure

9.1 Who can make a referral?

Referrals can be made by any individual, family members or other agencies such as charities, social services, NHS, GPs, schools, colleges or housing associations.

9.2 How to make a referral?

General enquiries and referrals can be made to the EB Community Support team by directly contacting the DEBRA EB Community Support Manager in the area or contacting the Membership team:

Email: membership@debra.org.uk

Tel: 01344 771961

Referrals can be made by:

- email
- telephone
- post
- in person

9.3 Complaints procedure

If the person making the referral or the client or the client's relative or representative wishes to make a complaint about the EB Community Support referral process or the service they have the option of having further discussion with their nominated EB Community Support Manager. If they are still unhappy they can raise the issue with their Regional Community Support Manager. If they feel the matter is still not resolved they can contact the Director of Healthcare, Membership and EB Community Support, Claire Mather, or submit a comment or complain through the DEBRA website (www.debra.org.uk/contact-us#feedback).

Claire Mather

Director of Healthcare, Membership and EB Community Support

DEBRA House
13 Wellington Business Park
Dukes Ride
Crowthorne
Berkshire
RG45 6LS

Email: claire.mather@debra.org.uk

Appendix 1 – support and services from the DEBRA EB Community Support team

The DEBRA EB Community Support team will offer you the best possible support we can regarding any non-medical needs resulting from living with Epidermolysis Bullosa (EB).

The Community Support team has a wealth of knowledge and experience which will enable us to support the EB community. A brief overview of the services we provide is detailed below:

We will work with you, to support you through issues associated with living with EB, but you remain fully responsible and in control of any actions taken or required. For example, the team can help with the process of completing benefit claims, but you as the client are responsible for the information given and for submitting the claim.

The Community Support service does not replace any statutory agencies, services or professionals.

We may need, with your consent, to refer you to or share information with another agency or professional to offer the most appropriate assistance. Without your consent information will only be shared with a relevant professional if we are legally bound to do so.

We are not employed as, and cannot give advice as, nurses, social workers or financial advisors.

We will ask for your consent to record all activities and actions on the DEBRA EB Community Support database. This is a confidential database for the DEBRA Community Support team.

If you would like a copy of your records please make a formal request in writing to the Director of Healthcare, Membership and Community Support.

Anonymised statistics on work carried out will be shared (e.g. 50 % of working time used to support people with matters related to benefits and housing).

The DEBRA EB Community Support team work closely with the clinical EB teams.

If you have any questions, please do speak to a member of the DEBRA Community Support team or contact DEBRA the Head Office on 01344 771961 or at membership@debra.org.uk.

Appendix 2 - DEBRA EB Community Support team EB referral cycle

