



BUTTERFLY BREAK RESPITE GRANT CRITERIA

PURPOSE:

DEBRA Australia works to support those living with EB and their families. A strong focus of our organisation is the emotional well-being of those living with EB. Our Family Support Program offers EB families, couples, or individuals an escape for some much-needed time away. Butterfly Breaks will focus on an opportunity to have quality time together, respite, relaxation, and a break from hospitals, medical clinics, and appointments.

WHO:

Butterfly Breaks may be accessed by:

- Individuals living with EB and their carer/partner.
- Parents and siblings who wish to have some time away together with the person with EB.
- Parents/carer/siblings of those living with EB who wish to access some respite and time away from the rigors of caring for a person with EB.
- Bereaved EB families

HOW:

Funds allocated to this program have been generously donated by DEBRA Australia. To access the funds for a Butterfly Break, an application process must be completed. As part of this process, the person/persons applying will need to specify the reason for the application, the persons attending the break, and their desired location. The chosen location/destination for travel must be within Australia, with a recommendation to select locations within the same state/territory of the applicants' residence, to maximize the grant allocation.

WHAT:

The grant will provide EB individuals/families with an opportunity to access funding to a maximum of \$2,000 per application. Any extra expenses are the responsibility of the recipient/s, and additional family guests are required to fund their own expenses. Funds of up to \$2,000 will primarily support accommodation expenses for 5 – 7 days, travel expenses, and/or meals for the family. A gift card will be given to the family for fuel and meal purchases. All funding will be transferred to the service provider or reimbursed to the applicant upon receiving a receipt of the purchase.

APPLICATION CRITERIA:

As there are a limited number of grants available, each applicant is required to submit their application via the relevant DEBRA Australia online application form, during the advertised period. This program will be advertised via social media, online, and via direct email to potential applicants. The advert will stipulate the aim/purpose of the respite program, the criteria/eligibility of who can apply, and the application process involved.





Application criteria include:

- Emotional and physical well-being of a person living with EB.
- Emotional and physical well-being of a person living with EB and their partner.
- Emotional and physical well-being of primary carer/guardian/parents/partner of those living with EB.
- Impact on family life of the daily routines of living with EB.
- Impact on a bereaved family/individual after their loved one passes away.

CONDITIONS:

- Only one application per EB individual and/or their family/carer may be submitted.
- If successful, members of this EB family cannot apply again for 2 years.
- Any person who has accessed a Butterfly Break in the last 12 months cannot apply for another one for a period of 2 years. This is to assist DEBRA Australia with providing equitable access to this grant.
- Individuals living with EB, 18 years of age and over, can apply for a Butterfly Break in conjunction with their primary carer/partner.
- Applications from individuals living with EB who are under 18 years of age can be submitted to include immediate family members or guardian/s, so long as they have not accessed a Butterfly Break in the last 12 months.
- Siblings/family members/guardians are not eligible to apply for funding if they are not directly involved with the regular care of an individual with EB.
- Bereaved families/individuals are eligible to apply.
- If the volume of applications received exceeds the program funding available, priority will be granted to the severest types of EB first followed by milder forms of EB.

PROCESS:

Applications will remain open until the program funding has been exhausted. Applications will be reviewed as received, with notification regarding the outcome of applications to be expected within 2 weeks from the application submission date.

- EB families will have the choice to select their preferred destination of travel.
- DEBRA Australia's Family Support Coordinator can assist, if needed, with accessing suitable accommodation in the chosen area.
- Travel must be taken before June 30, 2025.
- The grant amount of up to \$2,000 will be confirmed with successful applicants so that appropriate travel/accommodation arrangements can then be made.

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FURTHER CONSIDERATIONS:

- The Family Support Committee will work together to allocate the grants according to need, individual circumstances, and the suitability of the proposals received.
- The Family Support Coordinator will provide advice regarding family circumstances, physical well-being, emotional well-being, and the nature of the break, to assist decision-making.
- Families/individuals who access a Butterfly Break must be willing to share their experience with DEBRA Australia, to update relevant program sponsors. This should include providing feedback and photos about the Butterfly Break. Information provided may also be shared on various social media platforms.

