

Types of member contributions:

Volunteering	Lived Experience Involvement	Participation / Supporting
May or may not be affected by EB	Must have a direct experience of EB, usually DEBRA members	May or may not require direct experience of EB
Expectation at the start that you are giving your time (as opposed to money) to charity	Expectations at the start are varied and project-dependent	Expectations at the start are varied and project-dependent
Part of a formal scheme (volunteering in shops/office) with agreements and a 'line manager'	Not always within a formal structure / reporting line	Not usually part of a formal structure/agreement
Does not normally involve sharing aspects of your personal life	Can be an emotional toll of sharing aspects of your personal life	Can be an emotional toll of sharing aspects of your personal life
e.g. A shop or office volunteer, part of the formal volunteering scheme	e.g. Reviewing our research grant applications to help decide what research DEBRA will fund, joining a steering committee to direct a strategic project	e.g. talking about their personal experience of EB at a launch event, or giving feedback about a campaign