



Role Profile: Outreach Support Officer (Scotland)

Role:	Outreach Support Officer (Scotland)
Responsible to:	Director of Services
Pay Band:	Band 3 (£30,799 - £36,421 per annum FTE)
Key Contacts:	Director of Services, Outreach Support Officers, Communications Officer, Project Engagement Coordinator, volunteers, Duchenne community, external stakeholders such as neuromuscular centres, accessible sport venues, and hospices
Responsible for:	None
Location:	Scotland (home-based with organisation-funded travel across Scotland as required, and to London every 6-8 weeks)

This is a grant funded role, fixed term to July 2028, with the opportunity for conversion to a permanent role should funding allow.

Action Duchenne supports, empower and equip every DMD community in their journey from diagnosis and beyond.

Duchenne Muscular Dystrophy is a muscle wasting condition for which there is no cure, but we journey alongside communities to empower them and provide information for them to make informed decisions. Action Duchenne has a team of passionate, supportive staff who are keen to do more for families living with Duchenne and has several staff with direct lived experience.

At Action Duchenne, values are more than words—they shape how we work and interact every day. For this role, we are looking for a team member who can reflect our values:

- **Supportive** – Actively assist colleagues and stakeholders, fostering a culture of collaboration and reliability.
- **Empathetic** – Approach challenges with understanding, considering the impact on people internally and externally.
- **Respectful** – Ensure all communications and decisions uphold dignity and fairness, especially when handling sensitive matters.
- **Community Focused** – Make decisions that strengthen our community, ensuring all activity supports inclusive engagement and shared purpose.
- **Inclusive** – Promote accessibility and equity, ensuring everyone feels valued and heard.

Main Purpose of the Role:

To provide proactive, emotional, and practical support to families and individuals affected by Duchenne Muscular Dystrophy (DMD) across Scotland. The role will focus on early engagement, wellbeing assessment, community building, and delivery of workshops and events, while ensuring accurate tracking of support outcomes and data.

The successful candidate will also lead on support for young people living with Duchenne during end-of-life care, and their families as they face bereavement.

Specific Tasks:

1. Proactive Family Support

- Initiate contact with newly registered families within agreed timeframes (email within 3 working days, call within 7–10 working days)
- Contact to be made to all registered Action Duchenne members, known to us in Scotland, to ensure the current support offer is clear
- Provide ongoing support tailored to individual needs, including emotional wellbeing, physical health, housing, financial security, self-esteem and respect, decision-making, social engagement, quality of life, and access to care
- Use the Action Duchenne Assessment Form and Action Plan to identify and respond to areas of concern

2. Advanced and End-of-Life Care Support

- Provide compassionate, practical, and emotional support to children, young people, and adults living with Duchenne, and their families, as they navigate advanced stages of the condition and end-of-life care.
- Work collaboratively with healthcare professionals, palliative care teams, and hospices to ensure families have access to appropriate services and resources.
- Develop and share guidance, resources, and workshops to help families prepare for and manage advanced care planning, symptom management, and emotional wellbeing.
- Support families in understanding available options for care settings (home, hospice, hospital) and facilitate informed decision-making.
- Ensure continuity of care and communication between multidisciplinary teams, while respecting family preferences and cultural considerations.
- Offer signposting to bereavement support and follow-up services for families after loss.

3. Wellbeing Tracking and Outcome Measurement

- Administer wellbeing questionnaires and record scores across key domains (e.g. physical health, emotional wellbeing, financial security)
- Collaborate with families to co-create action plans and track progress
- Ensure all data is entered into CRM (E-Tapestry or similar) within the allotted timeframe, i.e. immediately after or during the call.

4. Community Engagement and Event Delivery

- Organise and deliver regional meetups (minimum one per quarter)
- Facilitate support groups (virtual and in-person) for parents, young people, and extended family
- Support delivery of workshops and events aligned with programme schedule (e.g. music, life skills, employability)

5. Stakeholder Collaboration

- Liaise with external organisations including NHS care advisors and clinics, local authorities, counselling services, and other charities
- Represent Action Duchenne in Scotland and build relationships with local networks

6. Administration and Reporting

- Maintain accurate records of all interactions and support provided
- Contribute to quarterly reporting on activity delivery, capacity utilisation, and family impact
- Support development of CRM processes and service delivery improvements

7. Key Performance Indicators (KPIs):

- New contact acknowledgement email: within 3 working days
- New contact follow-up call: within 7–10 working days
- Families contacted per week: 12–15 hours of direct contact
- Regional meetups: 1 per quarter
- Support groups delivered: 9–12 per year
- CRM data entry: within 24 hours of interaction
- Family outcomes tracked: via wellbeing questionnaire and action plan
- Advance Care Planning: Percentage of families supported with advance care planning discussions within 4 weeks of request
- Palliative Care Signposting: Number of referrals/signposts made to palliative care or hospice services
- Resource Development: Number of end-of-life care resources (guides, workshops, webinars) created and shared annually
- Number of families receiving end-of-life care guidance or resources per quarter.

NB This is not an exhaustive list, the role holder will be asked to carry out additional tasks as required for the Team’s successful service delivery. Such tasks will always be reasonable and broadly in line with current knowledge levels and skill sets.

Person Specification:

	Essential	Desirable
Education and Qualifications	<ul style="list-style-type: none"> • Good general education, no specific qualification required; relevant experience will be considered equivalent. 	<ul style="list-style-type: none"> • Understanding or training in one or more of the following areas: <ul style="list-style-type: none"> ○ Palliative and End-of-Life Care (including for children and young adults) ○ Communication during sensitive or distressing situations ○ Safeguarding of children and adults at risk (advanced level) ○ Trauma-informed and person-centred practice

		<ul style="list-style-type: none"> ○ Loss, grief, and bereavement support ● Emotional resilience and self-care in demanding roles ● Collaborative and multi-agency working across health, social care, and education ● <i>A qualification in health, social care, education, or a related field would be advantageous.</i>
<p>Knowledge and Experience</p>	<ul style="list-style-type: none"> ● Experience of the health and social care system in Scotland ● Significant experience supporting families or individuals with complex or long-term health, disability, or social care needs, providing both emotional and practical guidance. ● Experience working with people during periods of change, stress, or uncertainty, including transitions across health, education, or mobility stages. ● Strong understanding of how to identify support needs and respond through assessment, action planning, and coordinated signposting. ● Experience of maintaining accurate, timely records and managing sensitive information with professionalism and confidentiality. ● Proven ability to work both independently and collaboratively, prioritising workload, managing time effectively, and meeting deadlines. 	<ul style="list-style-type: none"> ● Experience working in the health sector or at a patient-led charity. ● Experience in health, social care, or patient-led charity sector ● Knowledge of Duchenne Muscular Dystrophy or similar conditions ● Familiarity with wellbeing assessment tools and outcome tracking ● Experience delivering transitions support or working in transitional care settings

	<ul style="list-style-type: none"> • Commitment to equality, inclusion, and person-centred practice, ensuring every family is treated with dignity and respect. • Great ability to communicate effectively, in writing and verbally. 	
<p>Skills and Aptitude</p>	<ul style="list-style-type: none"> • Passionate about improving the lives of young people, adults and their families living with complex health needs. • Emotional resilience and the ability to work calmly and professionally in situations involving complex health needs, including end-of-life support for children and young people. Demonstrates healthy boundaries, self-awareness, and the capacity to maintain stability and sound judgement when supporting families through distressing or sensitive circumstances. • A compassionate and empathetic approach, able to listen deeply, validate families' experiences and respond with sensitivity, respect and kindness. • A hopeful and strengths-based mindset, supporting families to identify what is possible, build confidence, and find a sense of direction during challenging periods. 	

	<ul style="list-style-type: none"> • Solution-focused thinking, with the ability to assess needs, prioritise effectively, and take proactive steps to address issues as they arise. • Highly developed verbal and written communication skills, including the ability to hold conversations involving sensitive, distressing, or complex issues, and discuss complex or difficult information with clarity, warmth and professionalism • A practical, 'can-do' approach, demonstrating initiative, reliability and the ability to follow through on actions to ensure families feel supported. 	
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Note: This role profile is not exhaustive and may evolve as the service develops. The post-holder may be asked to undertake additional duties in line with the role and their skills.