A qualitative evaluation of the impact of multidisciplinary group rehabilitation sessions and facial therapy for patients with a unilateral facial palsy and synkinesis.

Alison Benson – Indigo Research

Karen Young and Tamsin Gwynn – Queen Victoria Hospital

Executive summary

Sample

Sample comprised of 4 x 1½ to 2 hour focus groups,

18 respondents who had all participated in the MDT QVH FP programme.

All recruited directly from the data base and invited to take part in the evaluation by the facial therapy team. The sample covered a range of ages, time since onset and attendance of the programme from 2023 to 2025.

Interviews took place between 19th May to 1st June 2026 and all groups were conducted virtually on Zoom platform

Observations on the sample

- Respondents shared personal experiences in emotionally meaningful sessions, describing often prolonged journeys with Facial Palsy. They provided a rich and emotionally powerful exploration of the lived experience of Facial Palsy and participants' journeys through diagnosis, treatment, recovery and adaptation
- There was overall consistency in the themes participants raised, despite differences in age, background and duration of their Facial Palsy.
- The initial diagnosis was consistently described as traumatic and many felt unsupported in these early stages
- The sessions highlighted not only the significant physical effects of facial palsy, but also the often profound emotional, psychological and social impact that many participants experienced over prolonged periods.

Impact of Facial Palsy

- Two dominant themes emerged around the early challenges of diagnosis: these were getting access to the right care, help and support and learning to live with a visible facial difference and altered self-image
- All too often Facial Palsy can be perceived as a purely cosmetic issue, the ongoing and often quite considerable physical and functional impact such as eye closure, issues with eating, drinking, and speech often ignored or minimised

- The emotional and social burden of facial palsy emerged as one of the strongest themes in the sessions with participants repeatedly describing feelings of embarrassment, shame, grief, anxiety and social withdrawal.
- The discussion revealed how deeply facial palsy affected participants' sense of identity and confidence.
- Respondents also shared the impact on work related situations which had led to accommodations or different coping strategies over time
- Respondents described in moving terms, the changes they experienced over a period of time from diagnosis to starting treatment to where they are at now. This was seen to move through various stages of: shock, distress, frustration, acceptance and hope. This journey of acceptance can vary reflecting personal impact and time to access specialist support.

Sources of advice and information

- Sources of specific advice and information on Facial Palsy were hard to find with little direction from GPs, or HCPs about where to find relevant advice/ information or where to seek expert help. As a result there was heavy reliance on self-directed, independent research to identify treatment options and specialist services
- A limited number of sites were used to find expert help and FPUK was consistently mentioned as the only dedicated and expert resource
- Feedback on FPUK was overwhelmingly positive and many examples across the sample of using the site as a trusted resource and source of relevant information
- Particularly appreciative of the exercises, videos, emotional support of personal stories and advice on referrals to specialist centres at QVH and Oxford
- Some had participated in the online groups either for few initial sessions or for an interim measure until they were referred. These sessions were validating and reassuring but for some early on in their journeys – could be overwhelming and a realisation that their face may well not recover fully

Referral process

- A recurring frustration mentioned was the inconsistency of referral pathways and a lack of awareness about specialist Facial Palsy services.
- Most were only directed to QVH on basis of one chance recommendation via an HCP who they were lucky enough to stumble upon, or they eventually found QVH through self-searching, FPUK, online groups rather than a formal referral system
- Sessions also exposed widespread frustration with early healthcare experiences, and many described how their Facial Palsy had been minimised by healthcare professionals, both in primary and secondary settings.
- These included a lack of empathy and understanding, dismissive or insensitive comments from clinicians, a lack of information, follow-up or onward referral after diagnosis

- Referral times to QVH were also inconsistent with long delays and given the importance of early treatment and interventions this was especially frustrating
- Across the sample, arriving at QVH was described as a ‘game changer’ and there was the huge relief and appreciation of their first encounters with QVH
- Not only was the experience delivered in a way that felt compassionate and empathetic, but for the first time they felt they had a ‘road map’ of options and possibilities and they were now at the start of journey, not the end, and this was empowering

Overall feedback on the programme

- Overall feedback on the programme was extremely positive and appreciated as a unique, specialist well designed approach, incomparable to any other service for Facial Palsy
- The programme was described as well thought out, each element was appreciated and added clinical value and the MDT approach, overall structure and design of the individual elements felt comprehensive, holistic and unique
- It combines education as well as giving them the skills to help self manage and is delivered with expert clinical input that leaves most feeling, they are doing the very best they can to make positive changes to their Facial Palsy
- More importantly this is perceived as a partnership with QVH and in order to maximise the results and outcome they need to engage and exercise their face muscles regularly to both stretch and maintain any improvement
- The power of being a group participant was also regarded as a key benefit of the programme and for many an important element of the acceptance process
- Being part of the sessions demonstrated the value of peer support and shared experiences, and many described the relief of meeting others in similar situations. The group setting appeared to normalise experiences that many had previously felt isolated by and provided emotional validation
- The discussion demonstrated how powerful it was for participants to hear others articulate feelings they themselves had struggled to express.

Detailed feedback on the MDT programme and pathway of care

- Feedback regarding the QVH programme itself was overwhelmingly positive. Participants consistently described feeling genuinely listened to, understood and treated holistically for the first time. The expertise of the team inspired considerable trust and optimism
- Many participants contrasted the specialist knowledge and empathy within the programme against previous healthcare experiences where they had felt unsupported or dismissed. Participants particularly valued:
    - The specialist expertise of clinicians
    - Setting realistic expectations and giving a sense of hope
    - Clear explanations of facial palsy and synkinesis
    - Practical exercises and neuromuscular retraining
    - Emotional validation
    - Continuity of care
    - The supportive group environment

    - Input of relaxation and psychological techniques

- All elements were well received with the initial face to face session and consultation setting the tone and style of the programme
- Although the psychological assessment session was less consistent in how it was delivered, with some not receiving this element, it was a valuable addition and could be up weighted in future programmes
- The three sessions themselves were regarded positively overall, with high levels of education, sometimes technically detailed, practical exercises combined with the psychological input and relaxation techniques
- The relaxation elements, although not always appreciated at first, were soon recognised as an integral element giving an opportunity to relax, learn new skills and they valued the inclusion of this broader MDT approach
- The final one to one Facial therapy session was invaluable and offered a chance to reflect on what they had learnt, appreciate the visible differences and improvement both visually but also functionally, photographs worked well to demonstrate this evidence of positive change. They also enabled the therapist to refine stretches/ exercises to suit their own very specific needs
- Most were invested in the home exercise programme and recognised that although onerous and time consuming, this was really the only way to achieve consistent and long term change. Handouts were very helpful resources that were used further down the line as refreshers and helpful reminders to keep on track

Overall reported impact of the programme

- Across all sessions, everyone was able to identify the difference the programme had made to them physically in terms of appearance, functional benefits, emotional and psychological and more importantly, reaching a place of acceptance
- Many described moving from despair and helplessness toward acceptance, confidence and optimism. Although few described “complete recovery,” many explained that they now felt more in control of their condition and less dominated by it emotionally. Participants spoke of regaining confidence in work, social interactions and public visibility
- Some were also hoping for continued improvements as they moved on to further treatments with Botox, which was seen as integral to longer term management. All were enthusiastic about the number of visible benefits reported by those already receiving this

Refining the programme

- There were some low level suggestions for changes and improvements to the programme as currently structured, and these focused around a few key themes:
    - Including ongoing refresher sessions at different points of time in the programme
    - Summary sheets of key exercises

    - Wider access to psychological support and greater integration of the emotional support, this is both via the individual session but also making sure individuals have an opportunity to share their personal stories and to open up about emotional challenges they might have faced
- Other suggestions were around:
    - Building greater GP and HCP awareness and education
    - Earlier referral pathways, increased NHS awareness of Facial Palsy
    - Building more capacity via training and developing regional specialist centres
    - Ensuring good awareness of FPUK as the dedicated and excellent charity in this sector

The MDT Facial Palsy pathway is the gold standard of care that combines the very best that NHS can offer as a specialist and expert centre for treating and managing Facial Palsy – and it has been life changing for all lucky enough to be referred to the programme