

‘Perfectly Capable’ – the inaugural Dialysis Games

Introduction: The first Dialysis Games in the UK was held on 13th September 2015 in a local school sports facility. The event was the idea of a haemodialysis patient and took 2 years of planning and organisation by patient representatives and a MDT before coming to fruition.

Process: We provided taster sessions in badminton, boccia, 5-a-side and walking football, indoor bowls, new-age kurling, table tennis, adapted cycles, tennis, tai chi, yoga, Pilates and karate, linking with local disability sports groups, many of whom provided their services for free or at low cost. We also provided laughter and mindfulness therapies, hand massages by LUSH cosmetics, and interactive Indian cookery considering renal dietary specifications. There were bouncy castles, egg & spoon races, giant outdoor games, a raffle and a tombola. Representatives from the PKD charity and NKF manned information stands, alongside resource points for local sports opportunities, our local KPA, and the Organ Donation service. Risk assessments were conducted for all activities, first aiders and volunteers placed in every area to ensure patient safety. We provided a defibrillator on site. Guests were advised of the potential risks of participating in sports, especially if they had a recent health event, and disclaimers were signed. Plenty of rest areas and water/refreshments were freely available. All volunteers were briefed, provided with handbooks of essential information, had access to walkie talkies and a site supervisor. Fire wardens were assigned, and Public Liability Insurance was in place. A lunch and an evening BBQ, tailored to renal dietary requirements, were provided along with live entertainment and complimentary drinks as a finale. All participants were awarded medals sponsored by IMED Hospitals. The day was completely free to all who attended, aided by a very generous donation from BKPA. Total expenditure for the day itself was £4604.

Demographics: 25 patients, 34 adult relatives/carers, and 20 children attended the day as visitors. 27 volunteers supported the event, alongside 19 disability sports instructors and educators to deliver the activities. Of the patients 5/25 travelled from Wales and were HD dependent, the remainder were from our locality with 17 on HD and 3 on PD. Males totalled 16/25. The age range of patient participants was 22 to 90 years.

Outcomes: Feedback forms were supplied to adults; 10/20 returned from patients. Participants rated enjoyment of each activity. 15 people were encouraged to take up more sport post-Games, 2 not and 3 unsure. 9 considered joining local sports clubs, 2 not with 9 unsure. Overall feedback was positive: ‘it’s great to think I can still do things’, ‘very well organised, lots of activities to take part in, thanks for a lovely day’, ‘enjoyed the tricycle and new-age kurling was something I could do’, ‘everything was brilliant’, ‘boccia-loved it; badminton-thinking of starting; cycling-ace; football-good fun; kurling-loved it; karate-brilliant display’. Many constructive comments on how to improve subsequent Games were also offered.

Organisers cons were: a) disappointment at low patient numbers b) obtaining the necessary funds was hard work and time consuming although increased team bonding c) one patient sustained a fall but was managed appropriately -lessons taken to reduce the risk of a similar situation in future d) more time/people needed on the day to set up e) huge amount of time and energy to organise, so exhausting for us as well as the patients! f) insufficient planning to obtain feedback. Pros were a) patient engagement b) patients enthused to lead on developing new sports groups, eg renal football group with local football club support c) strengthening of team relationships, particularly with those who volunteered their time and services d) creation of new relationships with stakeholders e) multiple new skills learnt, eg website maintenance, logo design, licensing requirements f) raising profiles of renal physiotherapy and social work g) experience in event management h) total funds raised of £8000 to secure this and future Games.

Conclusions: It is important to offer patients and their families alternative experiences outside of their medical condition that have both health and enjoyment aspects in order to promote well-being and improve quality of life. Seeing patients actively participating in sports and activities away from their dialysis reaffirmed their strengths/resilience and was a positive experience for all. We plan to run future Games, establishing this as a regular event.