



## Associate Parliamentary Limb Loss Group

for the promotion within Parliament and Whitehall of the PREVENTION OF LIMB LOSS and the provision of prosthetic, orthotic, wheelchairs & special seating and other vital rehabilitation services/technologies for ALL PERSONS WITH LIMB LOSS in the UK and Internationally.

# SUSAN KRAMER MP REVIEWS “SHARED EXPERIENCES” BOOK – RELEASED BY ‘REACH’

## SHARED EXPERIENCES

### *Having and Parenting Children with Upper Limb Deficiencies*



Charlotte Fielder, with direct experience of limb loss, hosted a parenting workshop for REACH, the charity for Children with Hand or Arm deficiencies. Inspired by the stories she heard, Charlotte invited the parents to share their experiences. Parents from across the UK and Ireland responded with a strong desire to inform new parents, health professionals, teachers and a much wider audience, of what it's like and how it feels to have a child with limb loss.

Susan Kramer MP, a member of the [Parliamentary Limb Loss Group](#), writes:

*"Shared Experiences" is a wonderful, positive book that draws together the experiences of so many families with children who have upper limb deficiencies, not only to share their worries and difficulties but also to share their successes and joys.*

*When I was young, we often visited family friends whose beautiful little daughter was a victim of Thalidomide with very short arms and minimal hands. We all envied her gorgeous blond hair and classical beauty but she so often felt such utter frustration with her short arms and just being different that she would break out into anger hitting all of us children on our arms. She and her family, who felt very isolated, would have devoured Charlotte Fielder's book and its sense of all that is possible as well as its acknowledgement of the challenges.*

*The book focuses most on birth and the early years since, as Charlotte herself says, for older children "life has turned out well despite some bad experiences". It's an important message. And because the book has behind it the support of "Reach", it can link parents to a national organisation for support and advice.*

*This book is written with such loving kindness and yet such a recounting of real experience, that it will resonate with many who have never encountered upper limb deficiency but are aware that in our world, no-one faces life without challenges."*

**SHARED EXPERIENCES**

ISBN: 978-0-9563333-0-8

RRP £10 plus p&p

You can buy online at <http://www.reach.org.uk/>

All proceeds go to REACH

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**Editor's Note:**

"The birth of a child with congenital abnormalities of the limbs is a cause of great anxiety to the parents and family. They required an adequate explanation, reassurance that experts are available to give them detailed advice regarding these rare conditions.

Practical assistance and counseling - Provided other life threatening congenital abnormalities are absent, these children are expected to develop normally in the earlier months and until they are much older and start to compare themselves with their peers, they will not have the sense of loss associated with acquired limb deficiency. Such children instinctively tend to use the limbs they have to interact with the environment and to mobilise.

The management of these patients is effectively from birth through the individual's life, and involves various professional disciplines at different stages. It is made considerably more complex if more than one limb is deficient. In the early stages, it is primarily the parents who are being supported, with the emphasis is shifting progressively to the child as he or she becomes older. Unfortunately, the non-registration rate for adults with congenital upper limb deficiency would be as high as 84 per cent."

Source: AMPUTEE AND PROSTHETIC REHABILITATION – STANDARDS AND GUIDELINES – British Society of Rehabilitation Medicine (BSRM).



Susan Kramer MP