

Book Review

One family's story: Learning to live with chronic pain

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Evidence in Child Health to enhance Outcomes (ECHO; 2017). *One family's story: learning to live with chronic pain.* (eBook, available free of charge)

www.echo.ualberta.ca/en/Parents/KT%20Toolbox.aspx

Over a concise but powerful 48 pages, a team of researchers and clinicians from the Stollery Children's Hospital and the University of Alberta manage to convey a simple but outstandingly relatable narrative full of educational content for both children experiencing chronic pain and their parents. The booklet acts a guide to the initial steps of accessing care for children and families living with chronic pain, capturing a reader's attention by evoking the feelings, thoughts, and experiences faced by many families with a child who has chronic pain. The authors describe the progression of working with a chronic pain team to regain control over one's life despite pain, while striking a deliberate and meaningful balance between the educational content and validation of a family's journey to access care, putting forth a product as useful as it is accessible.

Written in first person from the perspective of the mother, the story follows a teenaged girl and her family through the journey of chronic pain diagnosis and treatment, focusing on the real struggles and experiences of all those affected by chronic pain. The story will hold many familiar moments for those who recall living with chronic pain prior to accessing care from a chronic pain service: the frustration of feeling as though you have tried every treatment, diet, and health care

provider possible, the tears and distress of siblings and family members, and the desire to help but having no idea how. The authors paint a vivid picture of the emotional toll for all involved: social alienation, guilt, helplessness, and hopelessness, but the narrative begins to change as the family learns of a clinic specializing in the treatment of chronic pain. The authors use the initial moments of meeting the interprofessional team at the chronic pain clinic as a means of tackling many of the major questions that families need to hear answers to—"Do you believe me?" and "Can you make the pain go away?". The authors cleverly provide dialogue between the family and clinician characters to conquer some of the key myths and misunderstandings encountered by families from well-meaning non-pain clinicians during their journey to find help. These include "We can't find anything wrong with her, so clearly there is nothing wrong with her" and "You, mom, need to stop coddling her."

By the end of the first clinic visit with the interprofessional chronic pain team, information regarding the treatment course is presented in a family friendly, accessible way, avoiding overly complex etiological and pathophysiological descriptions and medical jargon, instead focusing on positive aspects, such as the excitement generated at the prospect of resuming normal activities. The authors describe many of the strategies and treatments involved in chronic pain management, such as classes to become knowledgeable and skilled to manage chronic pain, cognitive behavioral therapy, mindfulness, and physical exercises; however, the focus is more

heavily on the philosophical approach of the chronic pain clinic, which is presented in succinct and memorable terms.

The book is beautifully illustrated in a simple, bright, colorful fashion reminiscent of any other children's book establishing a familiar friendly tone. The illustrations help to increase the accessibility of the content for those whom English is not their first language.

As a resource, the authors have provided some starting points for any family dealing with chronic pain, though have not attempted to replace the role of the clinic in educating the patient and family, instead providing an overview as to what to expect, underscoring the importance of seeking out specialized chronic pain care. Included is a series of useful example exercises, such as mindful breathing instruction and prompts for focusing on happiness, values and goals. Within the appendix is an index of terms that one might find useful as a reference in the beginning steps of their journey. The appendix is written in language that makes the definitions accessible regardless of one's educational background. Though some well-informed parents may find the explanations superficial, the simple terms provide an initial understanding that clinicians can build upon. A summary of the key components of chronic pain management are listed rather than explicitly described and thus act as a helpful "what to expect" section. Links to further resources are provided, including the websites of the Canadian Pain Coalition and the American Pain Society.

Overall, the writers, researchers, and illustrators of *One family's story* have created a

great foundational jumping off point for children and parents on their chronic pain journey. The only point of caution is that towards the end of the story, the mother states that chronic pain never goes away—"that is why it is called chronic;" however, this is not always true in pediatric chronic pain populations as not all children with chronic pain continue to experience chronic pain as adults. Although it is understandable that this message is meant to help children, adolescents, and their families move past seeking a cure and engage in evidenced informed strategies, this point may need some clarification by clinicians. Nevertheless, in a world populated by innumerable sources of opaque, terminology-heavy literature and websites, the authors have created a much needed product far more focused on simplifying the information and acknowledging the feelings, thoughts, and experiences of those involved. Their aim is to say, "you're not alone" and to guide children and families through the complex process of accessing of chronic pain specific resources. The ultimate lesson is aptly summarized in the adage "know pain, know gain", a message that will surely resonate with any child or parent on the first steps of their journey.

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