

# T.A.M.E. YOUR PAIN DAY PROGRAMME - COMPLEX PAIN SERVICE - CHW

## PRACTICE GUIDELINE®

### DOCUMENT SUMMARY/KEY POINTS

- The moderate intensity day programme is conducted by the complex pain service at the Children's Hospital at Westmead (CHW).
- Provides an overview of the CHW day programme including its purpose and inclusion/exclusion criteria.
- **TAME** is: **T**eaching **A**dolescents to **M**anage pain through **E**xercise and Empowerment

### CHANGE SUMMARY

- Due for review. Some changes throughout.

### READ ACKNOWLEDGEMENT

- The following staff are required to read and acknowledge they understand the contents of this policy:
  - Members of the Complex Pain Service
  - Staff members wishing to refer patients to the T.A.M.E. Your Pain day programme
- The following staff are to be aware of this policy:
  - All members of the Department of Pain Medicine

This document reflects what is currently regarded as safe practice. However, as in any clinical situation, there may be factors which cannot be covered by a single set of guidelines. This document does not replace the need for the application of clinical judgement to each individual presentation.

<b>Approved by:</b>	SCHN Policy, Procedure and Guideline Committee	
<b>Date Effective:</b>	1 <sup>st</sup> August 2019	<b>Review Period:</b> 3 years
<b>Team Leader:</b>	Nurse Practitioner	<b>Area/Dept:</b> Pain Management Unit CHW

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## 1 Introduction

Paediatric pain management is now recognised as one of the most important parts of patient recovery and well-being. Paediatric pain management has become a specialised field, characterised by an increased understanding of developmental neurobiology and pharmacokinetics, improved administration techniques, specific pain measurement tools and the use of adjunctive therapies.

The purpose of a Complex Pain Service is to encourage the appropriate treatment of pain by all medical personnel, supervise complex pain management regimens, provide an interdisciplinary approach to pain management, fulfil educational requirements at all hospital levels and conduct research into optimising the safety and efficacy of pain treatment techniques in children.

These guidelines are primarily for the management of persistent pain through a medium intensity paediatric day programme.

Whilst in the adult population chronic pain is often defined according to its duration, in the paediatric population it is often defined in terms of quality and mechanism and referred to as persistent or complex pain. As for adults, children can experience pain due to a disease process, an injury, as a functional somatic symptom or for no known reason. Persistent pain in childhood and adolescence is inconsistently reported with published prevalence ranging from 11 to 38% of the population. Evidence shows that paediatric persistent pain has consistently increased in prevalence in the past 20 years. While persistent pain occurs in children, it is most frequently reported in the 12-15 year age group. This is thought to be due in large part to pubertal development and its associated physical, cognitive, emotional, and social changes. A higher prevalence is reported in females.

For 3-5% of children and adolescents with persistent pain their life is negatively impacted including: poor sleep, reduced school attendance grades, leisure activities and friends, increased anxiety, depression, and a risk of victimization. They may also be perceived by peers as less likeable due to their friends' lack of understanding of what it is like to live with persistent pain. It is therefore important to treat early in order to prevent or minimise impact on the young person's developmental progress thus allowing a healthy transition to adulthood.

### 1.1 Classification of Pain

While anatomic and time-based classifications of pain remain important, a mechanism-based classification may be more useful.

#### 1.1.1 *Procedural (transient or physiological) Pain*

- Perception of acute nociception not associated with significant tissue damage or an inflammatory response. Does not outlast the duration of the procedure and has an obvious self-protective function.

#### 1.1.2 *Inflammatory (Acute) Pain*

- Nociception associated with significant tissue damage and an inflammatory response but does not involve damage to peripheral or central neurons. Typically postoperative or

trauma-related pain i.e. usually of recent onset and limited duration. Inflammatory pain occurs in the setting of local tissue injury where the injury does not overwhelm the body's reparative mechanisms: "healing" can occur without medical intervention. It is characterized by on-going activity and modulation of nociceptors and pathways as they innervate damaged tissues. This activity and its modulation are linked to inflammatory and healing processes within these tissues. The pain experiences associated with surgery and tissue damage may be termed a 'pain state', implying an altered neuro-physiology. This form of pain, expressed as hyperalgesia, spontaneous pain and allodynia, can be seen as a 'protective reminder system'- causing the subject to shield, protect and immobilize the affected body part.

### **1.1.3 Neuropathic Pain**

- The perception of pain associated with nerve damage either peripheral, autonomic or central. Typically, the damage sustained by the nervous system cannot be repaired e.g. limb amputation and spinal cord lesions.

### **1.1.4 Persistent Pain**

- Nociceptive responses associated with hyperalgesia, allodynia, spontaneous or referred pain and/or sympathetic dysfunction beyond the expected period of healing or in the absence of continuing inflammation. It may or may not be associated with a significant inflammatory response or neural damage. Typical examples: persistent headache, complex regional pain syndrome, recurrent abdominal pain, arthritis. Typically, this classification is used when symptoms occur for more than 6 weeks.

## **1.2 Day Programme**

- Evidence-based treatment of persistent pain in children uses a biopsychosocial approach with an initial emphasis on improvement in function, with a decrease or absence of pain expected after function is restored. It is mainly managed in an outpatient setting with the option for an inpatient rehabilitative program (within CHW) for children that are highly functionally impaired, in co-ordination with admitting teams A day hospital programme provides a medium intensity approach for those children that are not sufficiently improving in an outpatient setting, however not functionally impaired enough for an inpatient admission. Day programmes require a multidisciplinary team and train patients and their parents in self-awareness, realistic approaches to goal setting, motivation, problem solving and the establishment and sustainability of physical functioning, with the ultimate outcome of individuals changing their attitude and approach to pain.
- Pain programmes for the adult population are generally widely available and accessible, however paediatric programs are not as freely available. Adult programmes are not transferable to paediatrics as children are not simply 'little adults', differing both biologically and psychologically. The way children respond to injury is dependent on their developing nociceptive system and their pain has the potential to be modified by individual and parent psychological factors, ie, their beliefs, expectations, and perceived control. Paediatric day programmes are becoming increasingly prevalent across the

globe, with the common goal of improvement in function. . Definitive comparison of outcomes is not possible however with, due to variation in type and duration of treatment and an inconsistency in outcome measures.

## 2 Purpose

The primary purpose of the T.A.M.E Your Pain day programme is to:

- Improve awareness and understanding of the mechanisms of persistent pain for young people and their families.
- Improve the young person's self-management skills.
- Begin to develop lifelong pain management strategies and life skills.
- Reduce reliance on health services.
- Reduce reliance on pharmacological management of persistent pain.
- Reduce the impact pain has on the whole family.
- Transition the young person back into the routine of life prior to the experience of chronic pain.
- Focus on improvement in function rather than reduction of pain.
- Assist the young person to set achievable functional goals.
- Instill confidence in the young person and their family to manage their pain.

## 3 Structure

The programme is a medium intensity day program which is run for 5 days over a 2 week period in the NSW school holidays so as to not disrupt the young person's schooling. The programme involves structured exercises, training in pain self-management and coping strategies, education for the young person and their family, lifestyle management, and functional goal-setting.

Each programme will have a maximum of 6 and a minimum of 5 young people. All sessions are group based and no individual sessions are offered.

Each patient must be medically referred to a pain clinic for multi-disciplinary assessment of suitability.

A contract is required to be signed by the young person and their family prior to the commencement of the programme stating that all 5 days must be attended, and the young person is willing to participate in all activities to the best of their ability. The contract also stipulates that behaviours that are disruptive to the group environment will lead to being temporarily removed from the group and if absolutely necessary, the remainder of the program.

The programme is bulk billed by The Children's Hospital at Westmead.

## 4 Staffing

The programme is run with an inter-disciplinary emphasis which includes:

- Pain Management Staff Specialist
- Pain Fellow
- Nurse Practitioner or Clinical Nurse Consultant
- Physiotherapist
- Psychologist
- Other services may include Occupational Therapist and Hypnotherapist

## 5 Location

The programme is held in the high school room, Level One at The Children's Hospital at Westmead. Accommodation for rural patients will be arranged if available, for the young person and one carer.

## 6 Medications

As the emphasis of the programme is on the non-pharmacological management of pain, education about medicines will not be addressed in the group setting. An opportunity for individuals to discuss medications separately is available if needed.

Any individual taking medications must sign these in and out to the nurse during the programme. The nurse will dispense the medication as required. The nurse will maintain documentation of medication signed in and out and any dispensing of medication.

## 7 Questionnaires

Questionnaires via ePPOC (electronic persistent pain outcomes collaboration) are required to be completed by the young person and their parent/s or carer/s at the beginning and end of the programme, then at 6 and 12 months follow-up with the understanding that information provided within the questionnaires may be used for future research with all information de-identified.

## 8 Follow-up

Each young person will be allocated a staff member as their mentor who will be the person to maintain follow-up. Follow-up by the mentor will be attended to weekly via telephone for 4 weeks post program. Participants will be reviewed in the pain clinic in person or via digitalhealth one month post phone call completion. It is then expected that the young person

will return to their pre-programme services. At completion, the young person, referring doctor and any other relevant health professionals will be provided with a detailed written report on their progress through the day programme.

## 9 Inclusion criteria

- Each participant must have a corroborated clinical diagnosis or explanation (es) [through expert medical and other health care professional opinion and investigations (if appropriate)] regarding the cause/s of persisting pain
- All relevant and reasonable medical investigations have been completed, and the young person and their family accept the explanation for their pain or diagnosis
- Up to 18 years of age
- Attend high school
- Pain persists despite appropriate medical or surgical treatments
- Have trialled a multidisciplinary pain management approach, including physical and psychological strategies, despite which pain remains poorly controlled
- The young person has the capacity to understand and implement the content of the program
- Pain has had a significant impact on their lives which may include but is not limited to:
  - Pain interfering with school attendance and/or activity participation
  - Pain interfering with sleep
  - Requiring the assistance of another for activities of daily living
- Willingness to continue therapies as appropriate after discharge (e.g. physiotherapy, psychology)
- Willingness to participate in post-programme assessment/ questionnaires and 6 and 12 month questionnaires
- Ability to attend all 5 days and willingness to participate in ALL aspects of the programme
- Boundaries and confidentiality are agreed upon

## 10 Exclusion criteria

- No specific diagnosis or explanation as to the cause (-s) of persisting pain
- Ongoing medical investigations for the cause of pain
- Presence of psychiatric or psychological symptoms (cognitive, emotional or behavioural) that would preclude the ability to participate in all aspects of the programme
- Involvement in other interventions that may be counterproductive to the programme

## 11 Acknowledgements

- LEAP Program, St Vincent's Private Hospital, Brisbane
- Chronic pain day program, Boston Children's Hospital
- Adolescent Day Program, Bath, UK

## 12 References

1. Sullivan, M.D. "Between first-person and third-person accounts of pain in clinical medicine." In:ed. Pain – an updated review. IASP Press. 1999; 499-506.
2. Treede, R.D., Meyer, R.A., Raja, S.N. & Campbell, J.N. "Peripheral and central mechanisms of cutaneous hyperalgesia". Prog. In Neurobiology. 1992; 38: 397-421.
3. Price, D. D. "Psychological and neural mechanisms of the affective dimension of pain." Science. 2000; 288(5472): 1769-1772.
4. King, S., et al., The epidemiology of chronic pain in children and adolescents revisited: a systematic review. Pain, 2011. **152**(12): p. 2729-38.
5. Shah, R.D., D. Cappiello, and S. Suresh, Interventional Procedures for Chronic Pain in Children and Adolescents: A Review of the Current Evidence. Pain Practice, 2016. **16**(3): p. 359-69.
6. Weiss, K.E., et al., Acceptance of pain: associations with depression, catastrophizing, and functional disability among children and adolescents in an interdisciplinary chronic pain rehabilitation program. Journal of Pediatric Psychology, 2013. **38**(7): p. 756-65.
7. Perquin, C.W., et al., *Pain in children and adolescents: a common experience*. Pain, 2000. **87**(1): p. 51-8.
8. Palermo, T.M., C.R. Valrie, and C.W. Karlson, *Family and parent influences on pediatric chronic pain: a developmental perspective*. American Psychologist, 2014. **69**(2): p. 142-52.
9. Stahlschmidt, L., Zernikow, B & Wager, J, Specialized rehabilitation programs for children and adolescents with severe disabling chronic pain: Indications, treatment and outcomes. Children, 2016. **3**(33): p. 1-13.
10. Sled, M., et al., The economic impact of chronic pain in adolescence: methodological considerations and a preliminary costs-of-illness study. Pain, 2005. **119**(1-3): p. 183-90.
11. McGrath, P.A. and D.A. Ruskin, *Caring for children with chronic pain: ethical considerations*. Paediatric Anaesthesia, 2007. **17**(6): p. 505-8.
12. Finley, G.A., J. MacLaren Chorney, and L. Campbell, *Not small adults: the emerging role of pediatric pain services*. Canadian Journal of Anaesthesia, 2014. **61**(2): p. 180-7.
13. Eccleston, C., et al., *Adolescent social development and chronic pain*. European Journal of Pain, 2008. **12**(6): p. 765-74.
14. Forgeron, P.A., et al., Social information processing in adolescents with chronic pain: my friends don't really understand me. Pain, 2011. **152**(12): p. 2773-80.
15. Gauntlett-Gilbert, J.B., P, Living well with chronic pain: the role of pain-management programmes. BJA Education, 2018. **18**(1): p. 3-7.
16. Logan, D.E., et al., Changes in willingness to self-manage pain among children and adolescents and their parents enrolled in an intensive interdisciplinary pediatric pain treatment program. Pain, 2012. **153**(9): p. 1863-70.
17. Hechler, T., et al., Systematic Review on Intensive Interdisciplinary Pain Treatment of Children With Chronic Pain. Pediatrics, 2015. **136**(1): p. 115-27.

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