

## PROMOTING PAEDIATRIC PAIN MANAGEMENT

A project of the International Children's Palliative Care Network to challenge the myths that persist about assessing and managing children's pain, changing minds and practices to reduce unnecessary suffering.



#### What is children's palliative care?

We know that more than 21 million children in the world today live with a life-threatening illness or condition or one from which they will die before reaching adulthood.

Most illnesses and conditions bring with them unpleasant symptoms, the most common of which is pain.

Every day 21,000 children die. The vast majority of these children suffer needless physical pain and discomfort before and at the time of death.

Access to children's palliative care (CPC) reduces and relieves this suffering through the provision of holistic care by compassionate professionals with **expertise in pain and symptom control in children** while also offering psychological, social, emotional and spiritual support either in their own home, in a children's hospice or hospital.

When just one professional in contact with children with a lifethreatening illness is trained in the basics of CPC, many lives are improved. Children's pain and symptoms are relieved, their emotional, social and spiritual needs are met and families feel supported as they face the unimaginable.

Without appropriate training, health care professionals lack the skills and knowledge to control severe pain and unpleasant symptoms in children and most find it even harder to communicate

with honesty and empathy with the sick child and family members. Social, spiritual and psychological support for the dying child and their families is seldom prioritised or provided, leading to even greater suffering.

The greatest number of CPC services exist within the developed world. However, more than 90% of children who need palliative care live in the developing world, where services are either very localised or non-existent.

#### Why focus on pain management?

Pain is one of the major reasons why children present to health care facilities. Chronic or severe pain is a common presenting problem in children with complex, life-shortening or lifethreatening illnesses and conditions.

Despite much work being done to dispel them

over the past few years, there are still several myths that persist around childrens' experience of pain.



#### **MYTH #1**

Children become accustomed to pain.

#### FACT

Increased anxiety and pain perception occurs with repeated painful procedures.

#### **MYTH #2**

Babies and very young children will not remember painful procedures.

#### FACT

Repeated painful procedures in the newborn period can reprogramme and determine an individual's pain threshold for the rest of his or her life.

#### **MYTH #3**

Young children are less sensitive to pain than older children.

#### FACT

Many medical professionals still believe that due to an immature nervous system, young children are less sensitive to pain. Research has shown that younger children actually experience higher levels of pain than older children and adults.

#### **MYTH #4**

Children will tell you when they have pain.

#### FACT

Children may not tell you they are in pain due to fear of the treatment, inadequate communication skills or they may not be aware they are experiencing chronic pain as they know no different.

#### **MYTH #5**

Children are unable to show where it hurts.

#### FACT

Most children can point to an area on their body that hurts or on a drawing of a body.

#### **MYTH #6**

A child's behaviour reflects the intensity of the pain.

#### FACT

Children cope in unique ways. A lack of behavioural responses does not necessarily indicate a lack of pain.

#### **MYTH #7**

A child who is playing cannot be in pain.

#### FACT

While play is a distraction it is usually a way to help the child cope with pain and not an indication that the child is not in pain.

#### **MYTH #8**

Medical professionals are good at measuring pain in children.

#### FACT

Medical professionals consistently and significantly under-rate children's pain.

### How will this project solve this problem?

While there are numerous pharmacological and non-pharmacological methods that can be used to ease a child's pain, with the right knowledge and expertise it is entirely possible to eliminate a child's pain in most cases or, at the very least, to minimise it to a bearable level.

#### First step

The first and vital step in good pain management is to accurately assess and measure the frequency, type and level of pain the child may be experiencing.

The ICPCN has developed the digital **ICPCN Pain Assessment Tool for Children** that can be downloaded onto any smart phone via the iStore or Google Play store for free. This app allows a child, with the help of an adult where necessary, keep an accurate record of where the pain is located, how intense it is, the type of pain and whether anything relieves the pain. This information can be passed on to the medical professionals to help in assessing the efficacy of pain control measures.

#### Second step

Once assessed, medical professionals need to know how to treat and manage a child's pain. The ICPCN provides **a free online e-learning module** on pain assessment and pain management in children, available in 7 languages. This course, endorsed by the University of South Wales and based on the WHO Guidelines for Management of Persistent Pain in Children, can be accessed at www.elearnicpcn.org

The ICPCN also provides **face-to-face training on children's palliative care**, which includes an intensive day-long training module on pain assessment and pain management. To date we have provided this face-to-face training to over 1,000 health care practitioners in 24 countries, mostly in the developing world.

This project aims to ramp up awareness of the need for proper assessment and expert management of children's pain through encouraging the downloading and use of the ICPCN Pain Assessment Tool for Children and increasing the knowledge of pain assessment and treatment of medical professionals through face-to-face and online training on the assessment and management of pain in children.

#### **Potential Long Term Impact**

Research has shown that the provision of palliative care to a child, including the assessment and expert management of pain and discomfort, has the potential to vastly improve that child's quality of life. By training and mentoring doctors and nurses in palliative care, there is the potential to vastly improve the quality of life of thousands of children each year - with particular focus on those who have life-threatening illnesses such as cancer, heart disease, kidney disease, neurological conditions and numerous rare diseases.



Screens from the digital ICPCN Pain Assessment Tool App

#### How your donation will be used:

The ICPCN provides face to face training predominatly in Low and Middle Income Countries (LMICs), where there are few children's palliative care services. We train medical professionals and health care workers on the basic principles of CPC which includes a day-long training on pain assessment and pain management in children.

- \$10 pays for the download of the ICPCN Pain Assessment Tool for 5 children.
- \$20 pays for the download of the ICPCN Pain Assessment Tool for 10 children.
- \$25 pays for one medical professional from a LMIC to take the online ICPCN e-learning course on Pain Assessment and Pain Management in children.
- \$50 pays for one doctor/nurse from a LMIC to attend the entire 5 day face to face training course in the key principles of children's palliative care, including a day long training on pain assessment and pain management in children.
- \$100 pays for two doctors/nurses from a LMIC to attend the entire 5 day face to face training course in the key principles of children's palliative care, including a day long training on pain assessment and pain management in children.
- \$350 pays online hosting fees for the ICPCN Pain Assessment Tool App for a year.

Goal: £10,000







# **ABOUT ICPCN**

*ICPCN is the only international charity dedicated to securing the right of the twenty -one million children worldwide with life-limiting conditions to receive palliative care.* 

The International Children's Palliative Care Network (ICPCN) is a global network of organisations and individuals working in the field of hospice and palliative care for children.

We advocate at the highest levels for children's palliative care to be acknowledged and respected as a unique discipline within health care systems and provided by suitably trained and qualified people to all children with incurable or lifethreatening conditions and their families, regardless of where they live in the world.

We promote the concept that the care of babies, children, adolescents and young adults who face a shortened lifespan should include services, therapies and medications that will reduce pain and suffering and encompass all their physical, social, emotional, spiritual and developmental needs and that of their families, allowing for the best possible quality of life.

#### ICPCN C.A.R.E.S.

Key areas in which the organisation is active:

- C ommunication
- A dvocacy
- **R** esearch
- **ducation**
- S trategic development www.icpcn.org



# **OUR VISION**

"That all children living with life-limiting or lifethreatening conditions, and their families, will have seamless access to palliative care in order to alleviate serious health-related suffering and enhance their quality of life."