# Translation of the Palliative Care Toolkit into Nepali. (supported by PCW)

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बहिरङ्ग सेवा (OPD)
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अस्पतालको प्यालिएटिभ समूह
Draft Edition
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!य$ाए'टभ कयेर स म0ी
Palliative Care Toolkit (Nepali Edition)
!स!मत &ो र स धनकोप.रवशेमारहरे जरदैखिकोसवेमा सधुरा
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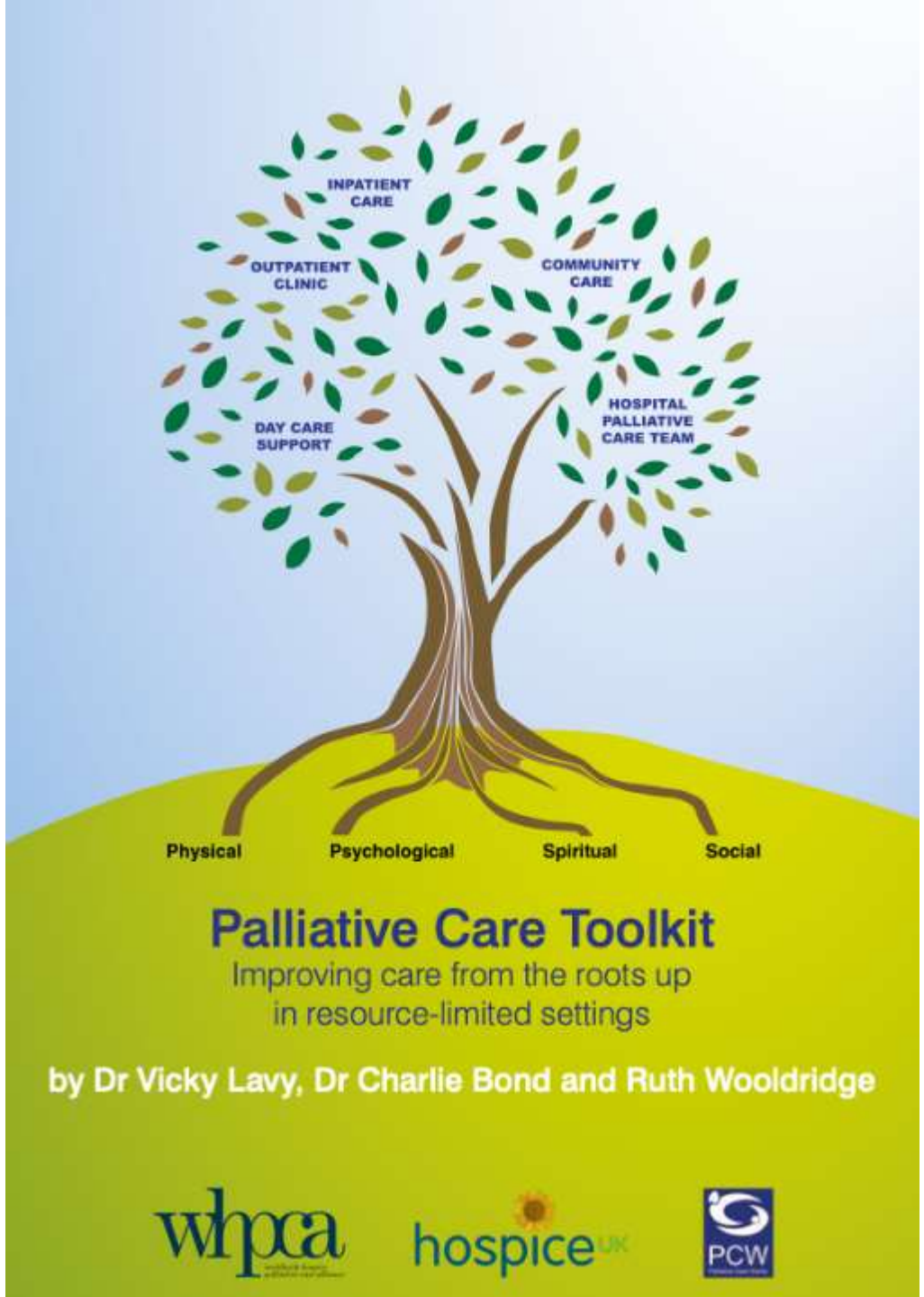
INPATIENT CARE
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# Nepali (Draft) Edition

The Nepali translation of the Palliative Care Toolkit was undertaken in April 2019 to January 2020 by kind permission and with the support of PCW. The project was led by members of International Nepal Fellowship Nepal (INF Nepal), Nepalese Association for Palliative Care (NAPCare) and the Gurkha Welfare Trust (GWT). The translation was completed after the reference group read the text and made suggestions for minor changes to the text to reflect the situation in Nepal: for instance giving HIV/AIDs slightly less prominence, promoting non-communicable diseases, such as COPD, commonly found in Nepal, omitting medications not available in Nepal and substituting these for other medications which are available. Some additional tools have been added namely: Integrated Palliative Outcome Scale (IPOS) translated into Nepali and the Supportive and Palliative Care Indicator Tools (SPICT-LIS). The translation was thoroughly checked by the reference group before the draft edition was published.

The Nepali Draft Edition will be used in training health workers in Nepal in 2020 and this will be evaluated later in 2020, following which the first edition of the Nepali Translation will be produced and made available for general use.

Members of the reference group for the Nepal translation:

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Dr Helen Douglas
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We would like to especially thank translator Ms Joyti Paryar for her translation work and Mr Prakash Paryar for setting the Nepali typescript.


TUBORG
GUEST HOUSE


भलायखर्क स्वास्थ्य चौकी
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Nepal's Hospice
and
Palliative Care Units
GREEN PASTURES HOSPITAL
BHAKTAPUR CANCER HOSPITAL

*Special Article*

# Opioid Availability and Palliative Care in Nepal: Influence of an International Pain Policy Fellowship

Bishnu Dutta Paudel, MBBS, MD, Karen M. Ryan, MA, Mary Skemp Brown, MBA, Eric L. Krakauer, MD, PhD, M.R. Rajagopal, MD, Martha A. Maurer, MSSW, MPH, PhD, and James F. Cleary, MD

*National Academy of Medical Sciences (B.D.P.), Bir Hospital, Ministry of Health, Kathmandu, Nepal; Research and Sponsored Programs (K.M.R.), University of Wisconsin; Pain & Policy Studies Group (M.S.B., M.A.M., J.F.C.), University of Wisconsin Carbone Cancer Center, World Health Organization Collaborating Center for Pain Policy in Palliative Care, Madison, Wisconsin; Department of Global Health & Social Medicine (E.L.K.), Harvard Medical School and Palliative Care Unit, Massachusetts General Hospital, Boston, Massachusetts, USA; and Trivandrum Institute of Palliative Care (M.R.R.), Pallium India/World Health Organization Collaborating Center for Training and Policy on Access to Pain Relief, Trivandrum, India*

DOI: 10.1016/j.jpainsymman.2014.02.011

# United Mission Hospital - Tansen

- 166 beds
- Medical, surgical, obstetric and paediatric services
- Serves rural districts in West Nepal and bordering Indian States

INTERNATIONAL NEPAL FELLOWSHIP

EMMSInternational
Health for Today, Hope for Tomorrow

UNITED MISSION HOSPITAL TANSEN


• 55 year old man, retired school teacher. Married with 2 sons age 30 and 24. Diagnosed with lung cancer 1 year ago. Treated in Kathmandu with chemotherapy and radiotherapy.
• He comes to see you in the health post with persistent cough. He looks much thinner than when you last saw him. He walks unsteadily and slowly with a stick.
• According to SPICT-LIS, how will you categorise him?
• What questions will you ask about his condition?
• What other important areas would you want to explore?
SPICT-LIS™

# Translation project

- INF –NAPCare - GWT
- Project team:
  - 9 doctors – pall med, oncology, GP
  - 3 nurses
  - Pharmacist
  - Public health researcher
- Discussed and agreed approach to translation – April 2019
- Cultural and clinical appropriateness – April – July 2019
  - Divided into sections: suggestions for changes
  - Changes circulated and discussed further

# Translation project

- Translation – *July – November 2019*
  - Experienced medical translator – translate each section *July – September 2019*
  - Team of doctor/ nurse/ researcher check and discuss translation
  - Initial translation finalized – *September 2019*
  - Individual sections – adaption teams for comment - *September - October 2019*
  - Translation agreed – *November 2019*
- Production – *November 2019 – February 2020*
  - Followed Toolkit style as much as possible
  - Chapters checked against Toolkit
  - Draft edition published

# Translation project (ongoing)

- Use Nepal Tookit in training *(postponed from March 2020)*
- Evaluated training *(after six months)*
  - What worked well/ not so well
  - What needs to change in Nepali Toolkit
- Project group discuss final changes for first edition
- Launch Nepali Palliative Care Toolkit *(Initially planned February 2021)*
  - *???When*


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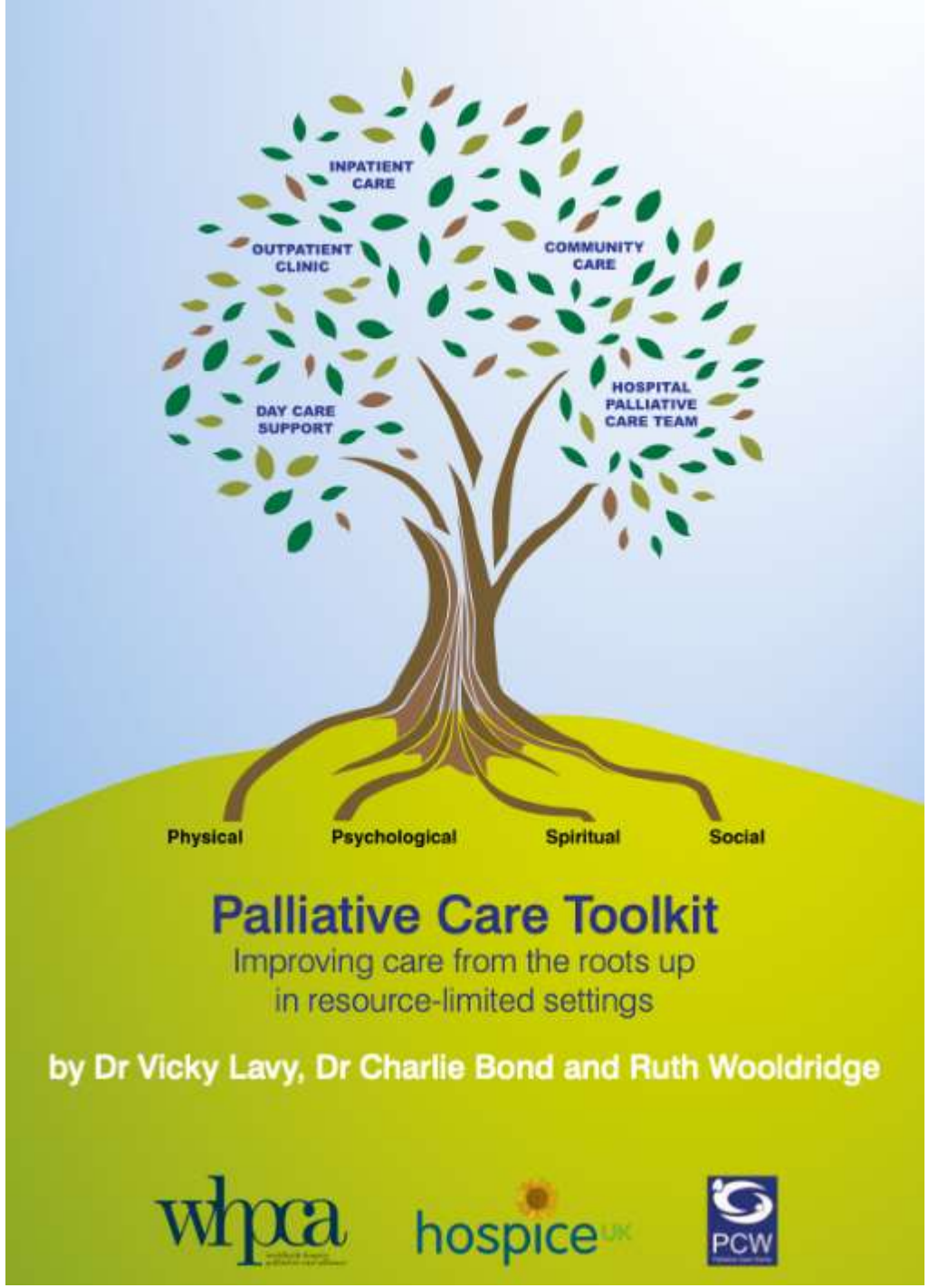
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# Main changes

- Changed order:
  - COPD, heart failure, cerebrovascular – common
  - HIV - not so prevalent
- All medication is available in Nepal
- Added Tools to Toolkit
  - Supportive and Palliative Care Indicators Tool for Low Income Settings (SPICT-LIS)
  - Nepal translation of Palliative Care Outcome Scale (POS)
- Added some photographs from Nepal
- Quotations

# भाग १: प्यालिएटिभ केयर भनेको के हो ?

प्यालिएटिभ केयर भनेको निको हुन नसक्ने रोग लागेका व्यक्तिहरूको हेरचाह गर्नु, पिडामा आराम दिएर उनीहरूको गाह्रो अवस्थामा सहयोग पुर्याउनु हो ।

## प्यालिएटिभ केयर भनेको के हो ?

जब बिरामीहरू निको हुदैनन् तब हामी के गर्छौं ? संसारभरि जुनै पनि ठाउँमा जहाँ प्रशस्त स्वास्थ्य कर्मीहरू, औषधिहरू, अत्याधुनिक उपकरणहरू भएता पनि बिरामीहरू निको हुन सक्दैनन् । उनीहरूलाई सहायता गर्न केहि गर्न सकिन्छ कि ? प्यालिएटिभ केयरले केही त्यस्तै गर्न खोज्दछ । विश्व स्वास्थ्य संगठनले प्यालिएटिभ केयरको परिभाषा लेखेको छ (तल हेनुहोस्) । हामी मध्ये धेरैलाई यो नयाँ तरिका हुन सक्छ । तर सरल रुपमा यसको अर्थ निको हुन नसक्ने रोग लागेका व्यक्तिहरूलाई हेरचाह गर्नु, पिडामा आराम दिनु र उनीहरूको गाह्रो अवस्थामा सहयोग पुर्याउनु हो । स्वास्थ्य कार्यकर्ताको रुपमा हामी मध्ये धेरैले हाम्रो दिन दिनको जीवनमा र काममा यस्तो वास्ता पुर्याउने किसिमका काम त गरेका छौं र पनि धेरै समस्याहरूसँग जुझ्न नसकिएर आफूले आफूलाई शक्तिहिन र निरुत्साहित भएको अनुभव गरेका छौं । सरल सीपहरू सिकेर आधारभूत जानकारीहरू पाएर दुवैलाई एकसाथ राखी निको हुन नसकेका बिरामीहरूलाई वास्ता गर्दा प्रभावकारी रुपमा प्रयोग गर्न मद्दत गर्न यो सामग्री लेखिएको छ ।

> विश्व स्वास्थ्य संगठनको प्यालिटीभ केयर परिभाषा
>
> प्यालिटिभ केयर भनेको त्यस्तो हेरचाह हो जसमा निको पार्न नसकिने रोग तथा रोग लागेका व्यक्ती र परिवारलाई गुणस्तर जिवन जिउन मदत गर्नु मात्र नभई व्यक्तिको दुखाई तथा पिडा र समस्याहरुको (शारिरीक, मनोसामाजिक र आत्मीक) समयमानै पत्ता लगाई त्यस्को व्यवस्थापन गर्नु हो।

## हामीलाई प्यालिएटिभ केयर किन आवश्यक छ ?

आधुनिक औषधि विज्ञानले पहिला रोगको उपचार गर्न औषधि , चिरफार र अन्य उपचारहरूको शुरुवात गर्यो । त्यसपछि हामीले "उपचार भन्दा रोकथाम" असल भनेर महसुस गर्यौं र स्वास्थ्य नाप, खोप कार्यक्रम र स्वास्थ्य शिक्षाको बारेमा जनस्वास्थ्यमा शुरुवात गर्यौं । हाम्रा धेरै जसो स्वास्थ्य सेवाहरू उपचार र रोगहरूको रोकथाम (अनुसार ढालिएका छन्) को लागि बनावट गरिएका छन् । तर यी सेवाहरूमा काम गर्दा, हामी मध्ये धेरैले एउटा ठूलो आवश्यकता नसमेटिएको पाएका छौं ।

प्यालिएटिभ केयरको आवश्यकता बृहत छ ।

- यस्तो अनुमान गरिएको छ कि विश्व व्यापी रुपमा हरेक वर्ष कम्तीमा पनि ४० लाख मानिसहरूलाई प्यालिएटिभ केयरको आवश्यकता पर्दछ । तल्लो र मध्यम तहको आम्दानी हुने देशहरूमा ७८% वयस्क र ९६% बालबालिकाहरूलाई प्यालिएटिभ केयरको आवश्यकता पर्दछ ।
- सन २०१२ मा क्यान्सरबाट मर्नेको संख्या आठ लाख भन्दा बढी छ । यी मध्ये ५.३ लाख अविकसित देशहरूमा छन्
- सन २०१२ मा HIV/AIDS (एच आई भी/ एड्स)बाट मर्नेको संख्या १.५ लाख छ ।
- ७०% भन्दा बढी मानिसहरू जटिल क्यान्सर अथवा एच आई भी HIV/AIDS को गम्भिर पिडाको अनुभवमा छन् ।



# Chapter 1: What is palliative care?

**Palliative care is all about looking after people with life-limiting illnesses, relieving their suffering and supporting them through difficult times.**

## What is palliative care?

What do we do when sick people do not get better? All over the world, even in places where there are many healthcare workers, plenty of drugs and the most modern equipment, there are patients who cannot be cured. Can anything be done to help them? Palliative care seeks to do just that. The WHO has written a definition of palliative care (see below). It may be a new term for many of us, but it simply means looking after people with life-limiting illnesses, relieving their suffering and supporting them through difficult times. As health workers, most of us have done some of this kind of caring at work and in our everyday lives but may have been unable to deal with many problems and felt powerless and discouraged. This toolkit has been written to help us to care more effectively by teaching simple skills and putting together basic information to use when we are caring for sick people who will not get better.

## Why do we need palliative care?

Modern medicine first set out to cure diseases with drugs, surgery and other treatments. Then we realised that prevention is even better than cure, and set about putting in place public health measures, vaccination programmes and health education. Most of our health services are designed for treatment and prevention of disease. But as we work in these services, many of us have found that there is a big need that is not being met: the ongoing care for those who do not get better.

> **WHO definition of palliative care**
> *Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.*
>
> www.who.int/cancer/palliative/definition/en

The need for palliative care is enormous.

- Over eight million people died from cancer in 2012. 5.3 million of these were in developing countries[1].
- One and a half million people died from AIDS in 2012[2].
- Over 70% of people with advanced cancer or AIDS experience severe pain[3].
- Over thirty five million people are currently living with HIV worldwide[2]. Only one third of them will have access to ARV's[5].
- It is estimated that worldwide at least 40 million people require palliative care each year. 78% of the adults and 96% of the children requiring palliative care are in low and middle-income countries[4].

The modern hospice and palliative care movement started in England in the 1960s with cancer patients. However, the need is even greater in resource-poor settings where cure is often impossible because of late presentation and limited treatment. The HIV epidemic has focussed attention on the need for palliative care. Even where antiretroviral therapy (ART) is available, patients still suffer difficult symptoms. Health workers can become demoralised as they see many patients whom they cannot help.

## भाग ४: तपाईले गाह्रो विषय वस्तुको बारेमा कुरा गर्न सक्नुहुन्छ

### सुनाइ

- बिरामीको तहमा बस्नुहोस् ।
- सक्रिय भएर सुन्नुहोस् र शान्त हुन दिनुहोस्
- कुराकानी पश्चात बुझे नबुझेको जाँच्नुहोस् ।

### बोलाइ (कुराकानी)

- आदरपूर्ण र नम्र हुनुहोस् ।
- असजिलो भाषाको प्रयोग नगर्नुहोस्
- कुराकानी पश्चात बुझे नबुझेको जाँच्नुहोस् ।

### अशुभ खबर बताउनु (भन्नु)

- व्यक्तिलाई कतिसम्म थाहा पाउन मन लाग्छ भनेर सोध्नुहोस् ।
- जसले खबर थाहा पाउन चाहन्छ, सो व्यक्तिबाट खबर नलुकाउनुहोस् ।
- जो खबर सुन्न तयार छैन् उसलाई जब्बरजस्ती नसुनाउनुहोस् ।
- झूट नबोल्नुहोस् ।

Be prepared = तयार हुनुहोस्

Relatives = नातेदार

Expectation = अपेक्षा

Assess what is appropriate = के ठीक छ भनेर जाँच्नुहोस्

Knowledge sharing = ज्ञानको बाँडचूड

Never “nothing we can do”= कहिल्यै पनि “हामीले केहि गर्न सक्दैनौ नभन्नुहोस्

Empathise = समानुभूति

Way forward = भावी योजना

Stop and reflect = रोकिनुहोस् र फर्केर हेर्नुहोस्

### आत्मिक सहयोग

Hope = आशा

Organized religion = धर्म व्यवस्थापन

Personal issues = व्यक्तिगत विषय वस्तु

Effect on our care = हाम्रो हेरचाहमा प्रभाव

### शोक

- गुमाउनुमा विभिन्न प्रतिक्रिया हुन सक्छन्
- समानुभूति र सहयोग प्यालिएटिभ केयरका भागहरू हुन्

# Indigestion/gastro-oesophageal reflux

This is common when there is pressure on the diaphragm from an abdominal tumour or ascites, and in neurological disease.

## Assess the patient

## Treat

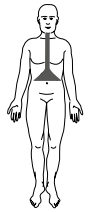
- Consider stopping NSAIDs or aspirin if these could be the cause.

## Care

- Nurse the patient in a sitting position.
- Give drugs after food.
- Try giving milk.
- Avoid spicy foods and alcohol.

## Prescribe

- Antacid, eg **magnesium trisilicate** suspension 10ml t.d.s.
- If persistent: **cimetidine** 200mg b.d. or **ranitidine** 300mg b.d. or **omeprazole** 20-40mg o.d.



# अपच अन्न नलीको पुनः प्रवाह (Indigestion/ gastro-oesophageal reflux)

जब पेटमा ट्युमर  बढ्छ वा जलोदर (पेट्मा पानि भरिने समस्या ) को कारणले डायफ्राममा दबाब पर्छ अथवा स्नायु सम्बन्धि रोगको कारणले  यो समस्या देखा पर्न  सक्छ।

## बिरामीलाई जाँच्नुहोस्

## उपचार गर्नुहोस्

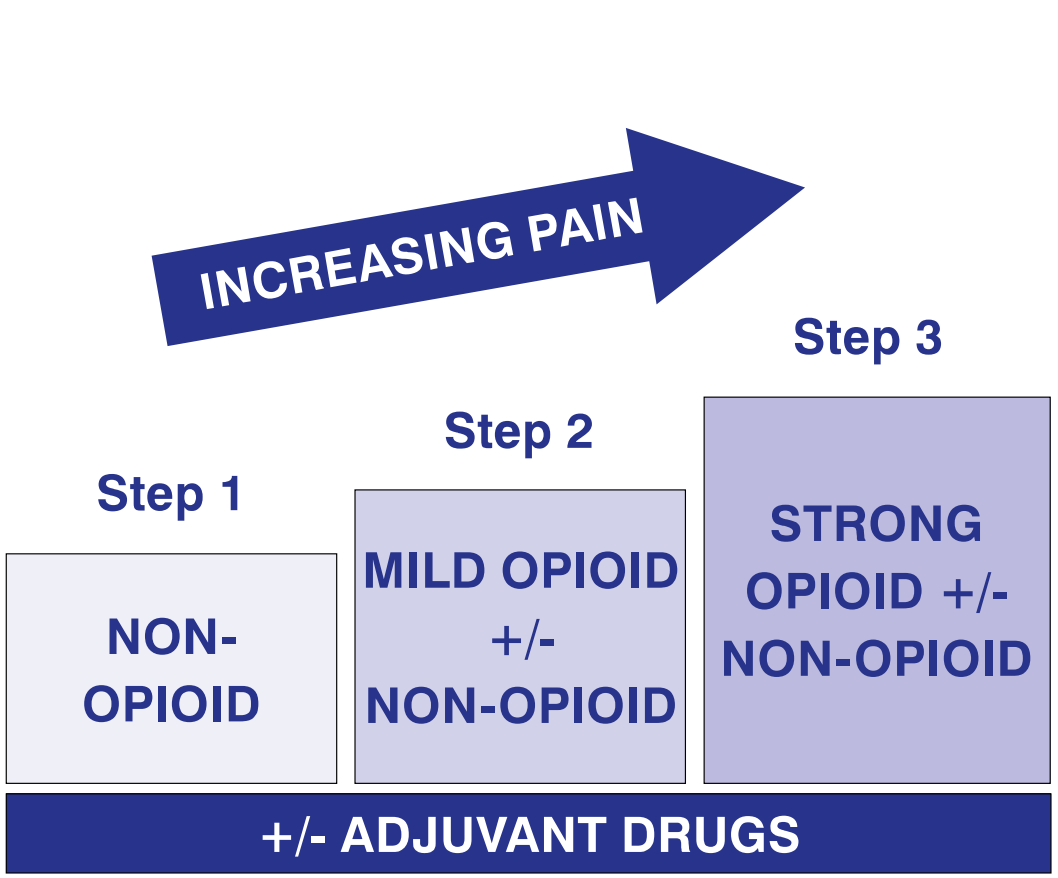
- यदि NSAIDS  वा Aspirin अपचको कारण हो भने बन्द गर्ने सोच्नुपर्छ।

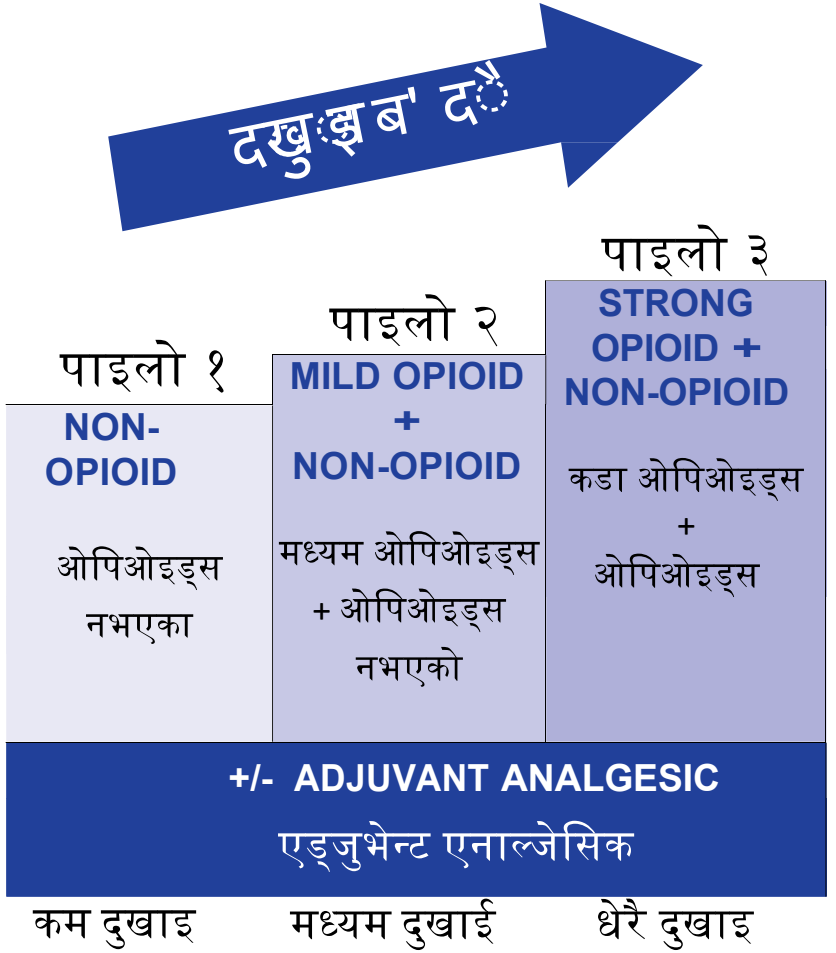
## हेरचाह

- बिरामीलाई सिधा बसालेर राख्नुहोस्
- खानापछि औषधी दिनुहोस्।
- दूध पिउनलाई उत्साह दिनुहोस्
- मसालादार खाना र रक्सि बाट टाढा बस्नुहोस्।

## तोक्नुहोस्

- एन्टासिड (Antacid) -  डायजेन (Digene)  १-२ चक्की वा १० – २० दिनमा ६ पटक
- र्यानिटिडिन (Ranitidine) १५० mg (150mg)  दिनमा २ पटक


INCREASING PAIN
Step 1
NON-
OPIOID
Step 2
MILD OPIOID
+/-
NON-OPIOID
Step 3
STRONG
OPIOID +/-
NON-OPIOID
+/- ADJUVANT DRUGS


दुखाइ
पाइलो १
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ओपिओइड्स
नभएका
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MILD OPIOID
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NON-OPIOID
मध्यम ओपिओइड्स
+ ओपिओइड्स
नभएको
पाइलो ३
STRONG
OPIOID +
NON-OPIOID
कडा ओपिओइड्स
+
ओपिओइड्स
+/- ADJUVANT ANALGESIC
एड्जुभेन्ट एनाल्जेसिक
कम दुखाइ
मध्यम दुखाई
धेरै दुखाइ

# आधारभूत औषधीको सूची (alphabetical) (सामग्री १७)

| Medicine name | Type of medicine | Clinical uses | Alternative drugs |
|---|---|---|---|
| Amitriptyline | Tricyclic antidepressant<br>Adjuvant analgesic | नशाकोदुखाइ p 41<br>उदासिनता p49<br>पसिना p43 | Dosulepin<br>Lofepramine |
| Amoxycillin | Antibacterial | छातीको संक्रमण p56+57<br>छाला संक्रमणp44 | Erythromycin |
| Aspirin | Non-opioid analgesic | दुखाइको उपचार p36<br>ज्वरो p43<br>मुखको घाउ p52 | Paracetamol |
| Bisocodyl | Laxative | कब्जियत p59 | Magnesium Hydroxide |
| Chlorpheniramine | Antihistamine | चिलाउनु p44<br>औषधीको छालाको प्रतिक्रिया p44 | Promethazine<br>Hydroxyzine |
| Codeine | Weak opioid analgesic | दुखाइको उपचार p37<br>पखाला p58<br>खोकी p56 | Dihydrocodeine |
| Co-trimoxazole | Broad spectrum antibacterial | संक्रमित पखाला HIV/AIDSमा p58<br>मूत्र संक्रमण p60-61<br>PCP prophylaxis | Chloramphenicol<br>Doxycycline |
| Dexamethasone | Corticosteroid<br>Adjuvant analgesic | पीडादायी सूजन p41<br>खानामा रुचि नहुनु p50<br>औषधीको छालाको प्रतिक्रिया p44 | Prednisolone |
| Diazepam | Benzodiazepine<br>Adjuvant analgesic | मांसपेशी बाउडीने p42<br>चिन्ता र अनिन्द्रा p48<br>श्वासप्रश्वासको कमी p57<br>मुच्छा पर्नु /काप्नु उपचार p46 | Lorazepam |
| Fluconazole | Antifungal | Candidiasis कयन्डिडिआसिस p52 | Ketoconazole |
| Haloperidol | Antiemetic<br>Antipsychotic | वाकवाकी र बान्ता p53-54<br>अलमल (छटपट र आवेगमा) p47<br>वाङ्ल्कीp55 | Chlorpromazine<br>Olanzapine |
| Ibuprofen | NSAID<br>(Non-opioid analgesic) | दुखाइको उपचार p36<br>सूजन - p41<br>ज्वरो p43 | Diclofenac<br>Naproxen<br>Indomethacin |
| Loperamide | Antidiarrhoeal | पखाला p58 | Codeine<br>Lomotil |
| Midazolam | Benzodiazepene | मुच्छा पर्नु /काप्नु उपचार p46 | Diazepam |
| Magnesium trisilicate | Antacid | अपच p55<br>नलीको पुनः प्रवाह p55 | Aluminium hydroxide<br>Magnesium hydroxide |
| Metoclopramide | Antiemetic | वाकवाकी र बान्ता p53-54 | Domperidone |

(सामग्री २०)

# SPICT-LIS™

THE UNIVERSITY of EDINBURGH

**The SPICT-LIS™ is used to help identify people in low-income settings whose health is deteriorating. Assess them for unmet supportive and palliative care needs. Plan care.**

## Look for one or more general indicators of poor or deteriorating health.

- Performance status is poor or deteriorating, best available treatment is having limited effect. (e.g. Stays in bed or a chair for more than half the day)
- Depends on others for care due to increasing physical and/or mental health problems.
- The person's carer needs more help and support.
- The person has had significant weight loss over the last few months, or remains underweight.
- Persistent symptoms despite best available treatment of underlying condition(s); is unable to access treatment (e.g. due to distance, cost or inability to travel).
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

## Look for clinical indicators of one or multiple life-limiting conditions.

### Cancer

Functional ability deteriorating due to progressive cancer.

Too frail for cancer treatment; treatment is for symptom control only, or treatment is unavailable.

### Dementia/ frailty

Unable to dress, walk or eat without help.

Eating and drinking less; difficulty with swallowing.

Urinary or faecal incontinence.

Not able to communicate by speaking; little social interaction.

Frequent falls.

Recurrent febrile episodes or infections; aspiration pneumonia.

### Neurological disease

Progressive deterioration in physical and/or cognitive function despite best available therapy.

Speech problems with increasing difficulty communicating and/or progressive difficulty with swallowing.

Episodes of aspiration pneumonia; breathless or respiratory failure.

Ongoing severe disability after stroke despite best available rehabilitation.

### Heart/ vascular disease

Heart failure or extensive, untreatable coronary artery disease; with breathlessness or chest pain at rest or on minimal effort.

Severe, inoperable peripheral vascular disease.

### Respiratory disease

Severe, chronic lung disease; with breathlessness at rest or on minimal effort between exacerbations.

Persistent hypoxia needing long term oxygen therapy, if available.

Severe respiratory failure during exacerbations.

### Kidney disease

Stage 4 or 5 chronic kidney disease with deteriorating health.

Kidney failure complicating other life limiting conditions or treatments.

Stopping or not starting dialysis.

### Surgical conditions

Severe burns with poor chance of recovery.

Serious condition with no access to surgical care; condition or health too poor for surgery.

### Other conditions

Deteriorating and at risk of dying with other conditions or complications that are not reversible (e.g. diabetes, sickle cell disease); best available treatment will have a poor outcome.

### Liver disease

Cirrhosis with one or more complications in the past year:

- diuretic resistant ascites
- hepatic encephalopathy
- hepatorenal syndrome
- bacterial peritonitis
- variceal bleeds

### Infections

Advanced TB with poor treatment response; multi-drug resistant TB.

HIV disease not responding to best available therapy.

AIDS related conditions:

- cryptococcal meningitis,
- pneumocystis pneumonia,
- encephalopathy.

HIV related cancer.

Cerebral malaria not responding to therapy.

Other infection not responding to treatment and deteriorating health.

## Review current care and planning; palliative care approach.

- Review current treatment and medication to ensure the person receives best available care; minimise polypharmacy.
- Consider referral for specialist palliative care review (if available) if problems are complex and difficult to manage.
- Agree a current and future care plan with the person and their family. Support family carers.
- Plan ahead early if loss of decision-making capacity is likely.
- Record, communicate and coordinate the care plan.

Please register on the SPICT website (www.spict.org.uk) for information and updates.

SPICT-LIS™ April 2018

# Future work

- Developing model of palliative care for remote areas
  - Network – district hospitals and health posts
  - All HCP basic training in palliative care
  - Mid-level workers with more in-depth training resource complex patients
  - ECHO groups
  - Basic tools – Toolkit and SPICT-LIS
- Integrated chronic disease management – including palliative care (primary palliative care)


THANK YOU