UCL Division of Psychiatry

Marie Curie Palliative Care Research Department

Getting palliative medications right in homes, hospitals, and hospices

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Putting big ideas into practice

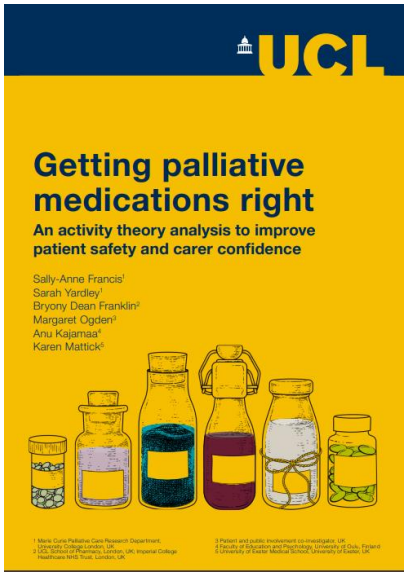
how can we improve patient safety and confidence?

≈ 20,000 pieces of published evidence

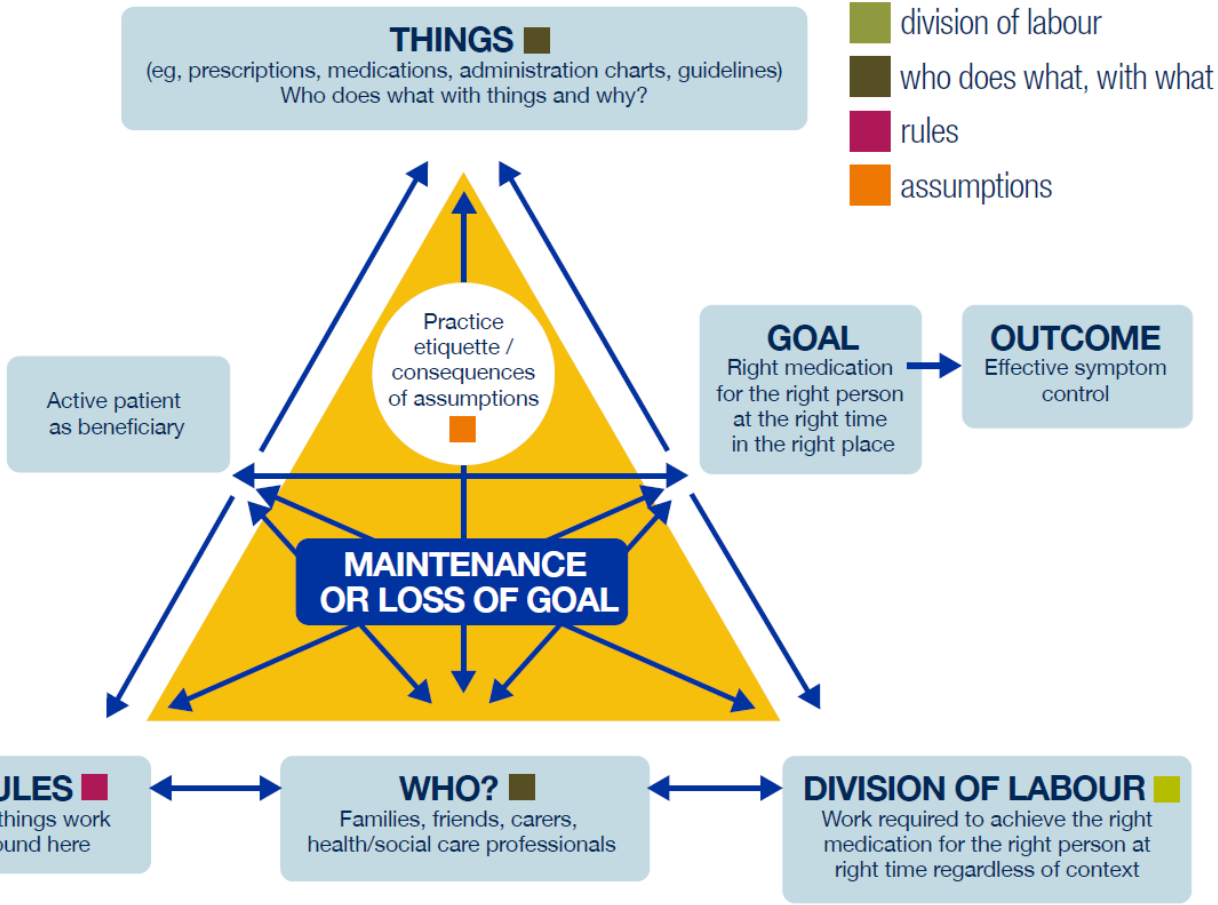
- 212 items named process steps but no practical detail
- 96 used to identify themes and active ingredients for an ideal model

Observations (120 hours) & Interviews (83)

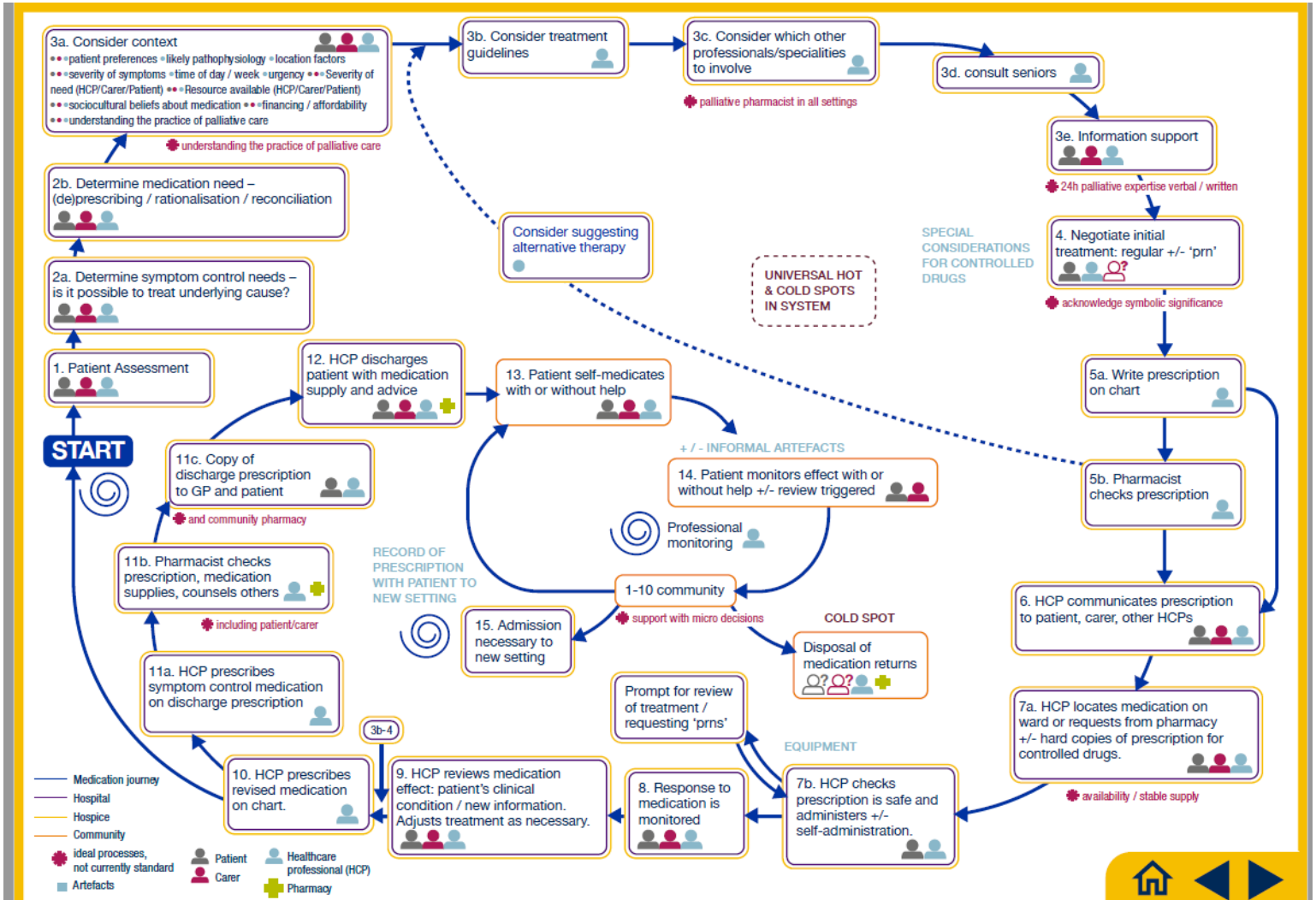
- Patients, carers and professionals
- Hospital, Hospice and Home (community)



Marie Curie


THINGS
(eg, prescriptions, medications, administration charts, guidelines)
Who does what with things and why?
division of labour
who does what, with what
rules
assumptions
Practice etiquette / consequences of assumptions
Active patient as beneficiary
GOAL
Right medication for the right person at the right time in the right place
OUTCOME
Effective symptom control
MAINTENANCE OR LOSS OF GOAL
RULES
How things work around here
WHO?
Families, friends, carers, health/social care professionals
DIVISION OF LABOUR
Work required to achieve the right medication for the right person at right time regardless of context


Getting palliative medications right


3a. Consider context
•••patient preferences •likely pathophysiology •location factors
•••severity of symptoms •time of day / week •urgency •••Severity of need (HCP/Carer/Patient) ••Resource available (HCP/Carer/Patient)
•••sociocultural beliefs about medication •••financing / affordability
•••understanding the practice of palliative care
understanding the practice of palliative care
3b. Consider treatment guidelines
3c. Consider which other professionals/specialities to involve
palliative pharmacist in all settings
3d. consult seniors
3e. Information support
24h palliative expertise verbal / written
4. Negotiate initial treatment: regular +/- 'prn'
acknowledge symbolic significance
SPECIAL CONSIDERATIONS FOR CONTROLLED DRUGS
5a. Write prescription on chart
5b. Pharmacist checks prescription
6. HCP communicates prescription to patient, carer, other HCPs
7a. HCP locates medication on ward or requests from pharmacy +/- hard copies of prescription for controlled drugs.
availability / stable supply
EQUIPMENT
7b. HCP checks prescription is safe and administers +/- self-administration.
8. Response to medication is monitored
Prompt for review of treatment / requesting 'prns'
9. HCP reviews medication effect: patient's clinical condition / new information. Adjusts treatment as necessary.
3b-4
10. HCP prescribes revised medication on chart.
11a. HCP prescribes symptom control medication on discharge prescription
11b. Pharmacist checks prescription, medication supplies, counsels others
including patient/carer
11c. Copy of discharge prescription to GP and patient
and community pharmacy
12. HCP discharges patient with medication supply and advice
13. Patient self-medicates with or without help
+ / - INFORMAL ARTEFACTS
14. Patient monitors effect with or without help +/- review triggered
Professional monitoring
1-10 community
support with micro decisions
COLD SPOT
Disposal of medication returns
15. Admission necessary to new setting
RECORD OF PRESCRIPTION WITH PATIENT TO NEW SETTING
Consider suggesting alternative therapy
UNIVERSAL HOT & COLD SPOTS IN SYSTEM
2b. Determine medication need – (de)prescribing / rationalisation / reconciliation
2a. Determine symptom control needs – is it possible to treat underlying cause?
1. Patient Assessment
START
Medication journey
Hospital
Hospice
Community
ideal processes, not currently standard
Artefacts
Patient
Carer
Healthcare professional (HCP)
Pharmacy

> “…if any of those [links] are disrupted or broken…it’s quite significant to what that outcome might be, it might be [a] really serious consequence… a rollercoaster from any of them… in your mind you think to yourself ‘oh that sounds like quite a straightforward process’ but things happen so much more fluidly.”

(Participant 76/77, Professional)

Hidden work – a carer's perspective

"

... But those two boys [care agency workers] looked after my husband as if he had been their grandfather… the sorted the medicine… I was finding it quite difficult.

[The GP] gave me a prescription … But then, when I got there – deliveries weren't coming in that day. I mean... probably, three occasions... I ended up either having to call back at the pharmacy later, which was quite a walk or saying, "I will take the prescription, and go to another chemist"… it was a bit of a mess.

And then, [GP] said, "really you should go to this other chemist, [who] had this connection with [the hospice] and I think had a sort of very ready supply of whatever there was in that carrier bag.

... people at home couldn't believe how long it took me to get the medicines.

That was before he went to the hospital... when he came out, [they] had altered all his prescriptions… I had to queue for hours…. waiting and waiting [at the hospital pharmacy]… we had these morphine patches which you had to change. It was a bit chaotic. I kept them on the side in the kitchen. And every four hours, I looked at them and we gave them whatever we thought was necessary. I think one of them was twice a day and some of them were four times a day, ... I was rather nervous of it.

(Participant 90)


Artefacts
(De)prescribing /rationalisation
Expertise/ Judgement
Monitoring/ review
Supply chain /access
Administration
Co-ordination of all palliative caregivers...
Administration
Admission Hospital / Hospice
INTENDED & IDEAL MEDICATION
Management Processes
Discharge
Home
CLICK HERE
...through reciprocal dialogue
STORIES
EXAMPLES


Routine availability of shared records across patients/carers, professionals and care settings. Delegation of care while retaining responsibility for medication. Availability of pharmacy professionals to contribute to medication decision-making. Transition management.
ARTEFACTS: Regulatory frameworks clinical guidelines, education and guidance documents, patient/carer self-management documentation (e.g. symptom scales), medication administration charts, prescriptions (FP10s and electronic), medications (including pre-filled syringes, crisis packs, anticipatory medication), labelling, administration equipment (e.g. CSCIs), storage including controlled drug cabinet and locked boxes.
Access to 24h drug information service with palliative expertise: medication choice, administration techniques, off-label use, information gaps. Guidance to support patients/carers with medication use, administration and individual advice.
Pharmacy professionals with palliative expertise as a resource for patients/carers/other care providers. Roles & relationships between prescribers/non-prescribers and generalists/specialists. Support for carers with micro decisions in medication management.
Artefacts
(De)prescribing /rationalisation
Expertise/ Judgement
INTENDED & IDEAL MEDICATION
Management Processes
Monitoring/ review
Supply chain /access
Administration
(DE)PRESCRIBING / RATIONALISATION: Specialist knowledge: optimising medication regimens, conversions/off-label use/drug compatibilities. Prescribing opiates: managing stigma/myths. Decision-making in context of concurrent disease / reversible acute causes of deterioration. Non-medical prescribing. Anticipatory prescribing. Interdisciplinary discussion and involvement of patients to reach deprescribing decisions. Effective disposal/returns.
EXPERTISE / JUDGEMENT: Multidisciplinary team, patient choice, involving families/carers, who does what? Contextual factors, work culture, attention to detail (knowing what has been tried before, reasons for stopping), discussion of risks/benefits, negotiations, safety netting opiates (dose adjustments, switching medications, rules), language/terminology, out-of-hours practice. Socio cultural beliefs about medication. Self-medication.
MONITORING / REVIEW: Medication regimen complexity. Positive culture of opioid safety. Feedback loop, evaluation, individualised care. Organisation, teamwork, advocacy. Roles, responsibilities, dynamics and documentation. Explanations to patients / carers / colleagues. Role of attitudes, beliefs and expectations. Understanding legal / ethical issues. Carer burden associated with managing medication and responding to symptoms.
SUPPLY CHAIN / ACCESS: Pharmacist oversight to medication management processes, core palliative medication stock lists in local pharmacies, routine availability of symptom control and anticipatory medication, and administration equipment where and when needed, efficient supplies with prescription changes, managing security and diversion risks, affordability of medication (free at point of access/insurance coverage/affordability).
All pharmacies to have a stock supply of basic palliative medications to understand/support urgent need/ practical challenges/pre-emptive prescribing. Routine access to specific palliative medication management support for carers.
Acknowledge symbolic significance of decisions about medication. Support carers re: concerns about potential medication errors. Expand options for carer involvement e.g. whole system approaches to carer-led subcutaneous administration of medication.
ADMINISTRATION: Complex medication regimens: dosage forms, routes, use of CSCI. Who is administering: professional/family carer – international variation in practice/perceived acceptability. Access to community-based staff for administration of injectables. Managing risks – interruptions. Carer anxieties about assessing need, appropriateness of medication, risk of overdosing. Co-ordination between different caregivers.
Shared information with community pharmacies to proactively plan for palliative patient and carer needs. Addressing inequities: neighbourhood variation in availability of palliative medication and controlled drug delivery services.
STORIES
EXAMPLES
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Universal system hot & cold spots

HOT SPOTS

Problematic areas with lots of attention such as out-of-hours care and the reliance on carers

- Lack of access to shared records
- Community Medication Administration Records (MAR)
- Hospital discharge processes
- Use of controlled drugs
- Syringe drivers
- Getting medications to patients at home

COLD SPOTS

Areas with less attention such as who takes responsibility for keeping carers informed of changes in medication at home and what is adequate support for safe medicines use at home

- Co-ordination of all caregivers
- Bringing patients and carers into the team
- Untangling lines of responsibility / recommendations / delegation
- Medication liaison work in transition
- Professionals' experience / understanding of all settings
- Functional feedback loops and reciprocal dialogue
- Support around safe use of medications when carers involved at home
- Practical and pragmatic workarounds (including hidden work and space for informed improvisation)
- Deprescribing
- What to do with medication after death

Patient · Carer · Healthcare professional (HCP) · Pharmacy

UCL

Getting palliative medications right

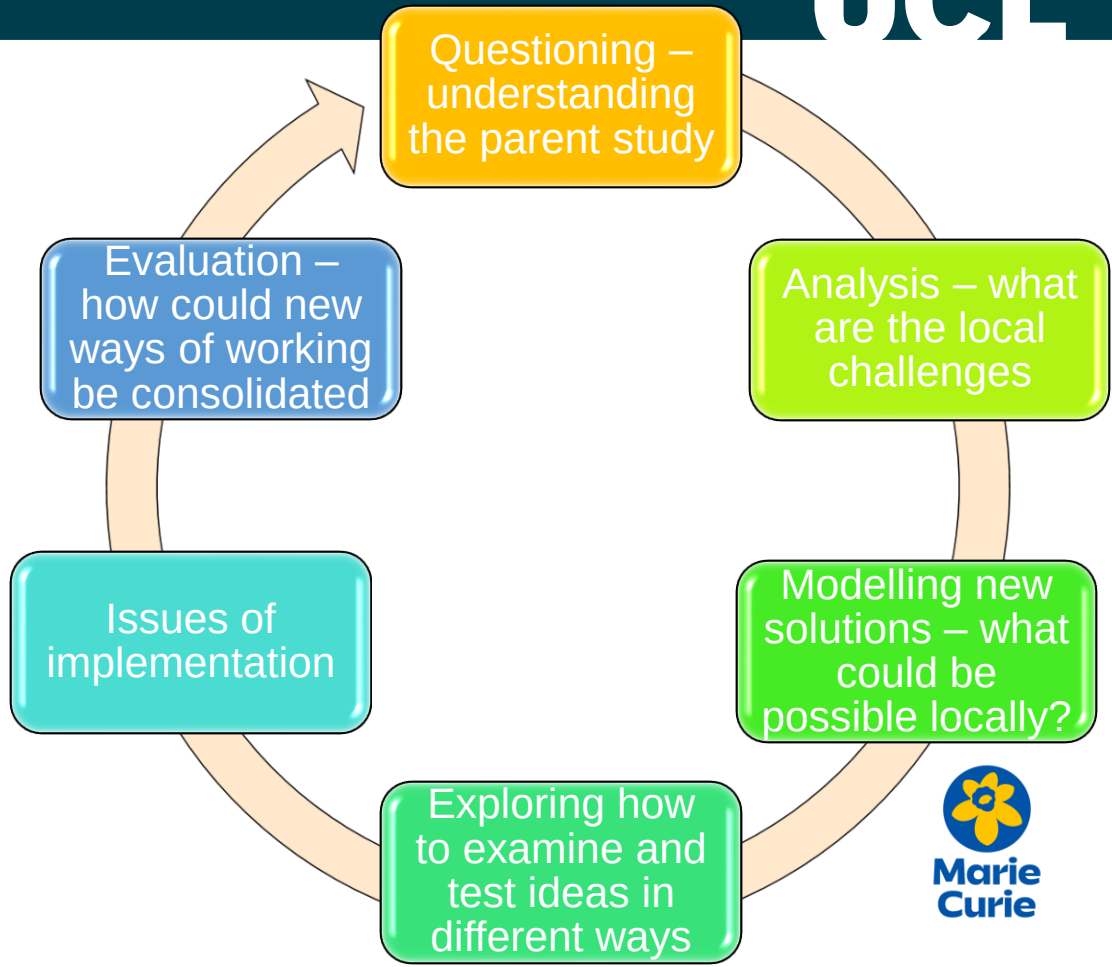
Marie Curie

STORY CONTENTS

1. **"I felt a bit like I was in an Agatha Christie story"**
   [Carer]
2. **"…the ones that are a bit more mysterious to me actually are the key medicines"**
   [Patient]
3. **"– a relationship of trust – so that we can bring about changes in their drugs and keep them on board with us"**
   [Hospital Professional]
4. **"if the patient is in pain or the patient needs it, I personally won't walk out and say, "sorry, I've got to wait five hours"**
   [Community Professional]
5. **"There's lots of liaisons between teams"**
   [Hospice Professional]

Activity system evaluation framework

- Four different Marie Curie places
- To co-produce a customised list of local priorities to improve medication management
- To develop one co-designed improvement project per local site
- To share an approach to identifying problems and implementing change at a local level, which can be re-applied



Workshops

Identified pain points in existing processes - where it doesn't function or is problematic

What is in your control and what can you influence? Stepping stones and roadblocks towards achieving your goal

Modelling solutions

FUNDED BY Marie Curie

Over to you...

Identify a shared pain point

What are the opportunities for change?

- Buds, thorns and roses

How will we know a change is a success?

- Plant, nurture, grow, harvest


TOP TIPS: **PATIENTS AND CARERS**

Getting palliative medications right at home, in hospital and hospice

Good to know...

- Healthcare staff can help you more if you are able to be completely open about how you are managing all your medication at home – it is normal to find it challenging.
- You can ask for a medication review with healthcare professionals including your pharmacist. It is okay to ask if all medications are necessary.
- If you have been in hospital or hospice, you should get a summary of your current medication when you leave. Show to any healthcare professionals who visit you.

Red flags – what's imp

- If you are not using medication how it
likes/dislikes, difficult to use, awkward
adjust it with you.
- If swallowing a tablet becomes difficult
for help rather than just stopping.
- If you are given 'just in case' or anticip
know where this is being kept and ask

What works well...

- Being organised with medication at ho
actually using even if these are differe
- When a medication is started or chang
symptoms) you should be looking out f
medication you do not need anymore.
- Tell your pharmacy if you are receiving
offer any help with your medication (e.

Who can help with cha

- Hospital/hospice staff can help you pre
discharged before you go home.
- Healthcare professionals should explai
including what to do if you need urgent
useful phone numbers.

Where did this come from?
www.ucl.ac.uk/psychiatry/research/mar
curie-palliative-care-research-departme
research/activity-theory-analysis

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TOP TIPS: **HEALTH AND SOCIAL CARE PROVIDERS**

Getting palliative medications right at home, in hospital and hospice

Good to know...

- It is never too early to involve palliative care colleagues when symptoms are difficult to control.
- Small differences matter. You can help patients and/or carers by explaining the reasons for changes to prescribed medication, including if the appearance of medication has changed.

Red flags – what's important to share...

- It is important to agree with people preferred ways to communicate e.g. text/email and to have a backup mode if you don't get a response or are unsure if messages are getting

ue visiting the patient are different, there
e most appropriate prescription. Creating
rgent) can save time overall and make care

to self-administer medication or for carers to
ich appointment, giving support if needed.

dministrative staff) about palliative
it from the right person can be as efficient

ge and experience of managing medication
nical responsibilities when possible. Giving
t is needed.

colleagues (getting to know each other,
diaries, dialogue, and discussion) can lead
e system effectiveness.

ges?

ded as part of the medication team.

mmunity pharmacy technicians) can review
nd feedback to healthcare staff.

ve signed up to the Daffodil Standards for
le to offer extra support.

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SYSTEM QUALITY INDICATORS

Getting palliative medications right at home, in hospital and hospice

- All patients and nominated carers to be included as part of the palliative care team. Make it easier for patients to nominate someone to act on their behalf regarding logistics and practicalities around medication management. Ensure patients have a call-back number to get medication-related problems sorted for 24-48 hours post-discharge from hospital/hospice.
- All palliative care patients receiving medication for symptom control to have direct and regular access to a pharmacist, trained in palliative care. All patients to receive a structured medication review and have shared decision-making conversations about deprescribing.
- Increase commissioning of palliative care pharmacists in community services, acute hospital teams as well as hospices and enable working across boundaries.
- Train healthcare professionals to support carers through education initiatives regarding micro decisions about medication (e.g. deciding when to administer 'when required' medication) red flag symptoms and side effects, adapting to changes in medication and carer-led administration.
- Everyone in the system (irrespective of place of practice) including the patient/carer, to have access to live GP medication records and access to hospital/hospice discharge summaries. This is not the same as access to universal or electronic care plans. All prescribers to have access to live drug charts, i.e. Medication Authorisation and Administration Record (MAAR) charts in the community on electronic systems.
- Encourage healthcare professionals to rotate periodically into other locations and settings, e.g. hospice, hospital, and community. Commissioners/policy makers to work with local providers to increase real time dialogue for transitions (e.g. hospital discharge) and complex care handover – partly technology enabled (such as increased availability to work mobile phones for staff) and partly cultural change.
- Out-of-hours palliative care services to deliver care using appropriately trained and experienced healthcare professionals. Create mechanisms for staff to be flexible around a patient's needs when dealing with a patient who is alone or only has one carer (e.g. not needing to leave a dying person alone to get medications).
- Set-up systems so that availability of, and point of access to, 24/7 supplies of palliative medications is coordinated by professionals and shared with prescribers, patients, and families. Consider systems to use hospital pharmacies as back up for community access out of hours.
- Identify and increase the number of community pharmacies working to Royal Pharmaceutical Society/Marie Curie Daffodil Standards and those willing to deliver palliative medications to patients at home.
- All community and hospital pharmacies to accept medication returns when someone has died.

Where did this come from?
www.ucl.ac.uk/psychiatry/research/marie-curie-palliative-care-research-department/research/activity-theory-analysis

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Rewilding healthCare

If you are traveling by boat, sometimes the best way to get to where you want to be involves sailing a different course, a different direction, rather than trying to go directly. This is because tides and currents move you even as you sail through the water. ‘Course made good’ describes the best course to take accounting for how you will be influenced along the way by things out of your control.