Prescribing for Just In Case bags : top tips for getting it right.

Dr Sarah Human, Consultant in Palliative Medicine, Rowcroft Hospice.

This Session

- **When** to prescribe
- **What** to prescribe
- **How** to prescribe
- Useful resources
- Questions

“Hoping for the best, prepared for the worst, and unsurprised by anything in between”

Maya Angelou,
“I know why the caged bird sings”, 1969

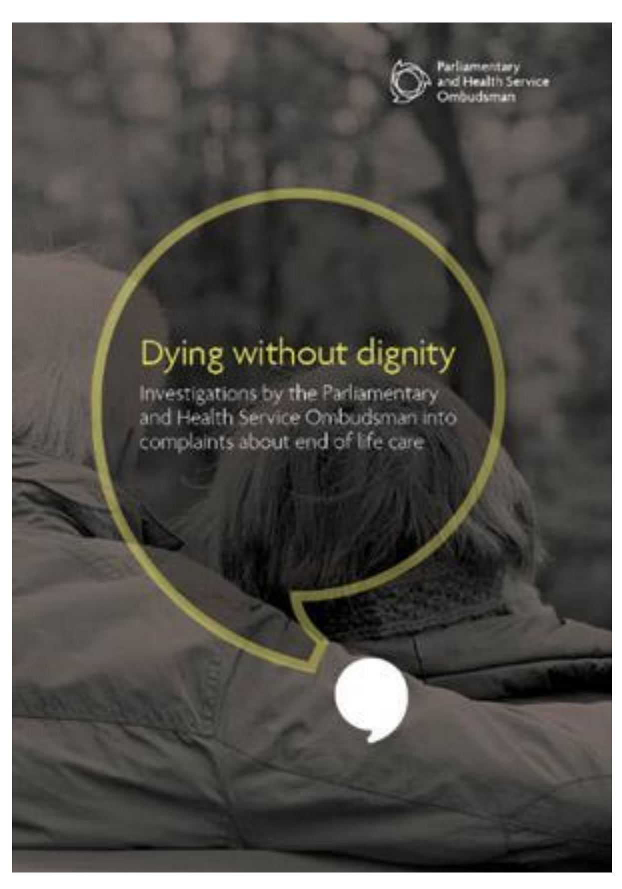
Just In Case Bags

- Anticipatory prescribing (AP) is the prescribing and dispensing of injectable medications in advance of clinical need
- Adaptable to individual circumstances e.g. renal failure, Parkinson’s, bowel obstruction

Just in Case Bags

- Enabling quicker administration of key medications in the patient's home
- Intended for use when sudden *(but expected)* deterioration in patient's health and unable to take orally
- Improve chances of patient remaining in their preferred place of care

https://www.ombudsman.org.uk/sites/default/files/Dying_without_dignity.pdf



Not recognizing dying

Poor symptom control

Poor communication

Inadequate OOH services

Poor care planning

Just In Case Bags

"The availability of such medication in the patient's home is in no way a substitute for proper clinical evaluation at the time of a change in the patient's condition".

"The prescriber needs to be satisfied that the patient and carers understand the reasons for the medications. This is a good time to discuss the prognosis with the patient and their family, and to ensure they understand how to access care if their health deteriorates"

https://www.bma.org.uk/advice-and-support/gp-practices/prescribing/anticipatory-prescribing-for-end-of-life-care

Just In Case Bags

"Drugs remaining in the community for extended periods of time".
"Prescribing for the future: it inevitably involves uncertainty and risk concerning the drug's correct use when it does come to be used".
"Doctors who prescribe drugs in this way have very little control over what will happen when the drug is actually administered".
"There is a concern that advance prescribing might encourage their administration without proper assessment".

https://www.bma.org.uk/advice-and-support/gp-practices/prescribing/anticipatory-prescribing-for-end-of-life-care

Prognostication

Why is it important?

- For patients
- For family/carers
- For health and social care professionals

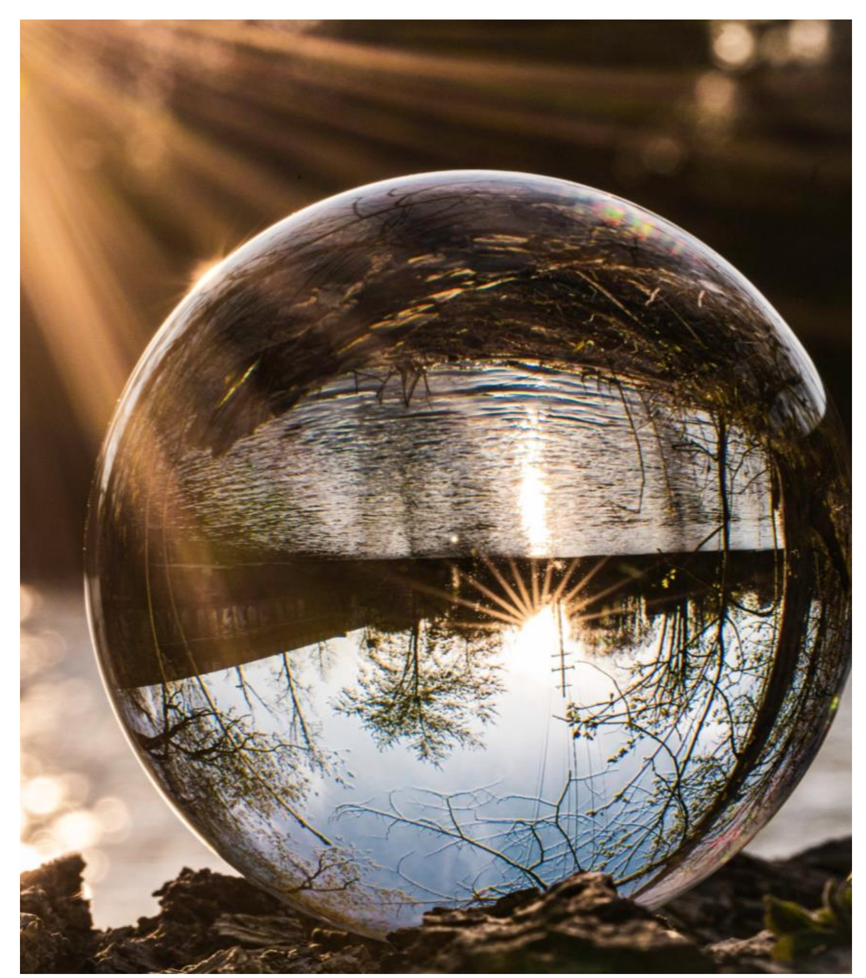
"Assessing needs not measuring time"

Encouraging engagement in conversations

"Talking about what really matters"

Collaboration across disciplines

Alters goals of care



”Doubt is an uncomfortable condition, but certainty is a ridiculous one”

Voltaire

Dosa DM. A day in the life of Oscar the cat. New England Journal of Medicine. 2007 Jul 26;357(4):328-9.

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CARL COURT/PA WIRE/PA PHOTOS

The evidence suggests clinicians tend to over-estimate prognosis

All looked at cancer, and some showed that ‘clinician prediction of survival’ can be useful / may add something.

But all demonstrated over-optimism.

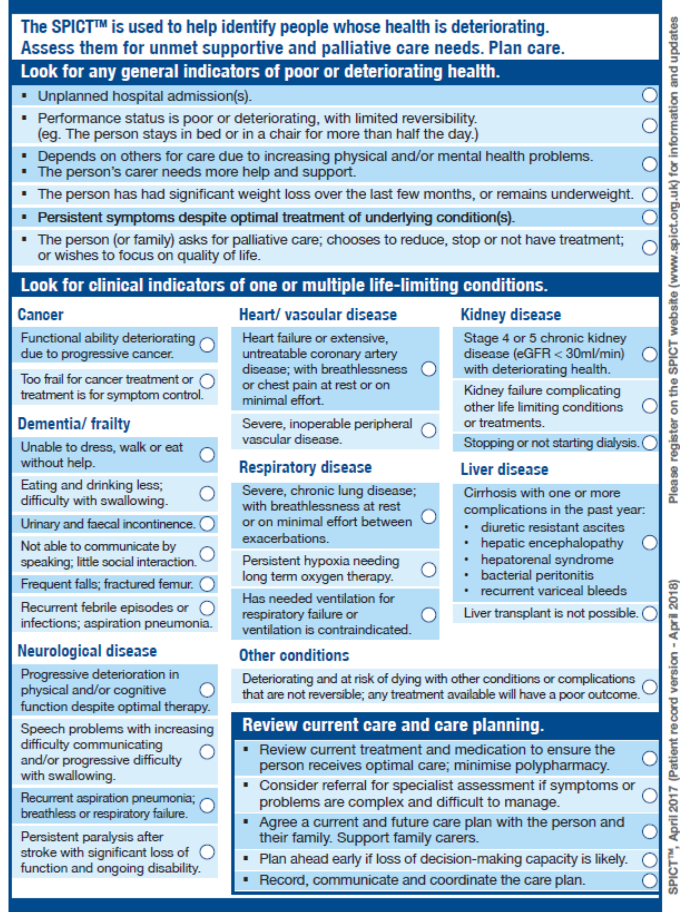
Showed MDT better than doctors or nurses alone.

- *C. Murray Parkes 1972*
- *Christakis and Lamont 2000*
- *Glare et al (Systematic Review) 2003*
- *Gwillam et al 2013*

Prognostication – what tools are out there?

THE UNIVERSITY of EDINBURGH

Supportive and Palliative Care Indicators Tool (SPICT™)



The SPICT™ is used to help identify people whose health is deteriorating. Assess them for unmet supportive and palliative care needs. Plan care.

Look for any general indicators of poor or deteriorating health.

- Unplanned hospital admission(s). ◯
- Performance status is poor or deteriorating, with limited reversibility. (eg. The person stays in bed or in 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 optimal treatment of underlying condition(s).** ◯
- 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 or treatment is for symptom control. ◯

Dementia/ frailty

- Unable to dress, walk or eat without help. ◯
- Eating and drinking less; difficulty with swallowing. ◯
- Urinary and faecal incontinence. ◯
- Not able to communicate by speaking; little social interaction. ◯
- Frequent falls; fractured femur. ◯
- Recurrent febrile episodes or infections; aspiration pneumonia. ◯

Neurological disease

- Progressive deterioration in physical and/or cognitive function despite optimal therapy. ◯
- Speech problems with increasing difficulty communicating and/or progressive difficulty with swallowing. ◯
- Recurrent aspiration pneumonia; breathless or respiratory failure. ◯
- Persistent paralysis after stroke with significant loss of function and ongoing disability. ◯

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. ◯
- Has needed ventilation for respiratory failure or ventilation is contraindicated. ◯

Kidney disease

- Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health. ◯
- Kidney failure complicating other life limiting conditions or treatments. ◯
- Stopping or not starting dialysis. ◯

Liver disease

- Cirrhosis with one or more complications in the past year: ◯
  - diuretic resistant ascites
  - hepatic encephalopathy
  - hepatorenal syndrome
  - bacterial peritonitis
  - recurrent variceal bleeds
- Liver transplant is not possible. ◯

Other conditions

- Deteriorating and at risk of dying with other conditions or complications that are not reversible; any treatment available will have a poor outcome. ◯

Review current care and care planning.

- Review current treatment and medication to ensure the person receives optimal care; minimise polypharmacy. ◯
- Consider referral for specialist assessment if symptoms or 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. ◯

SPICT™, April 2017 (Patient record version - April 2018) Please register on the SPICT website (www.spict.org.uk) for information and updates

Performance/functional Scores e.g., Karnofsky, WHO

Prognostic Indicators e.g., Gold Standard Framework, SPICT

"The Surprise Question"

General indicators

Specific clinical indicators e.g., cancer, heart failure, COPD

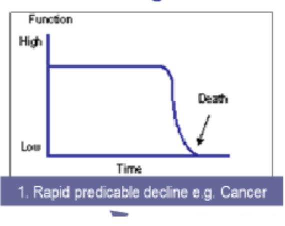
The Gold Standards Framework
Proactive Identification Guidance (PIG)

The National GSF Centre's guidance for clinicians to support earlier identification of patients nearing the end of life, leading to improved proactive person-centred care.

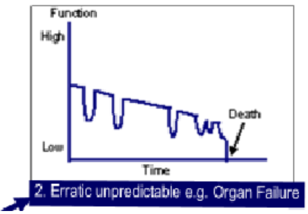
GSF PIG 7th Edition June 2022 Keri Thomas, Max Watson (HUK), Julie Armstrong Wilson and the GSF team
For details see http://www.goldstandardsframework.org.uk, https://www.goldstandardsframework.org.uk/PIG, https://www.gsfinternational.org.uk/pig-tool

Proactive Identification Guidance – identifying patients' decline earlier, enabling more proactive care.
This updated 7th edition of the GSF Proactive Identification Guidance or PIG (previously known as the GSF Prognostic Indicator Guidance), aims to enable the earlier identification of people who may need additional supportive care as they near the end of their life (see GMC and NICE definition of end of life care), to include final year of life as well as final days. This includes people with any condition, in any setting, given by any care provider (not just those needing specialist palliative care), following any trajectory of decline for expected deaths (see below). Additional contributing factors when considering prediction of likely needs include underlying co-morbidities, current mental health and social care provision etc.

Three Trajectories of Illness (Lynn et al)
reflecting the three main causes of expected death



1. Rapid predicable decline e.g. Cancer



2. Erratic unpredictable e.g. Organ Failure

Definition of End of Life Care General Medical Council
GMC - https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life
NHS - https://www.nhs.uk/conditions/end-of-life-care/what-it-involves-and-when-it-starts/
The GMC definition of End of Life Care, used by the NHS, NICE and others is 'People are 'approaching the end of life' when they are **likely to die within the next 12 months**. This includes people whose death is imminent (expected within a few hours or days) and those with:

- Advanced, progressive, incurable conditions.
- General frailty and co-existing conditions that mean they are expected to die within 12 months.
- Existing conditions if they are at risk of dying from a sudden acute crisis in their condition.
- Life threatening acute conditions caused by sudden catastrophic events.'

NICE Guidance in End of life care 2021 Identification
https://www.nice.org.uk/guidance/qs13/chapter/Quality-statement-1-Identification
'Statement 1 Adults who are likely to be approaching the end of their life are identified using locally developed systems.'

https://www.goldstandardsframework.org.uk/PROACTIVE-IDENTIFICATION-GUIDANCE-PIG

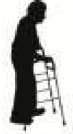
Clinical Frailty Scale*

1 **Very Fit** – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.

2 **Well** – People who have **no active disease symptoms** but are less fit than category 1. Often, they exercise or are very **active occasionally**, e.g. seasonally.

3 **Managing Well** – People whose **medical problems are well controlled,** but are **not regularly active** beyond routine walking.

4 **Vulnerable** – While **not dependent** on others for daily help, often **symptoms limit activities.** A common complaint is being "slowed up", and/or being tired during the day.

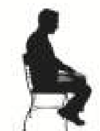


5 **Mildly Frail** – These people often have **more evident slowing,** and need help in **high order IADLs** (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.

6 **Moderately Frail** – People need help with **all outside activities** and with **keeping house**. Inside, they often have problems with stairs and need **help with bathing** and might need minimal assistance (cuing, standby) with dressing.

7 **Severely Frail** – **Completely dependent for personal care,** from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).

8 **Very Severely Frail** – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.



9. **Terminally Ill** - Approaching the end of life. This category applies to people with **a life expectancy <6 months**, who are **not otherwise evidently frail.**

Scoring frailty in people with dementia

The degree of frailty corresponds to the degree of dementia. Common **symptoms in mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In **moderate dementia**, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In **severe dementia**, they cannot do personal care without help.

* 1. Canadian Study on Health & Aging, Revised 2008.
2. K. Rockwood et al. A global clinical measure of fitness and frailty in elderly people. CMAJ 2005;173:489-495.

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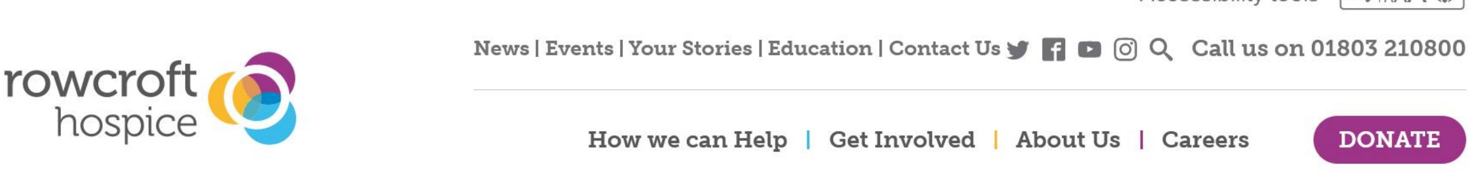
Just in Case Bags

WHEN to prescribe

- Patient is deteriorating and approaching end of life: prognostic indicator guidance
- Consider TEP/End of Life Register

https://rowcrofthospice.org.uk/how-we-can-help/hospice-care-south-devon/planning-for-the-future-hub/



Planning for the Future Hub

Just in Case Bags

WHEN NOT to prescribe

- When the patient doesn't want them
- When repeated SC medication for symptom control required
- Risk assess if concerns regarding misuse/diversion

SIPRESS

"Don't freak out—it's just a save-the-date."

Original Article

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Administering anticipatory medications in end-of-life care: A qualitative study of nursing practice in the community and in nursing homes

Eleanor Wilson[1], Hazel Morbey[2], Jayne Brown[3], Sheila Payne[2], Clive Seale[4] and Jane Seymour[1]

Potential symptoms at the end of life

- Pain
- Colic
- Nausea and vomiting
- Respiratory secretions
- Breathlessness/cough
- Restlessness/agitation
- Seizures

Just in Case: What To Prescribe

Appendix A

PRESCRIPTION AND MEDICATION ADMINISTRATION RECORD FOR USE WITH JUST IN CASE BAGS

This prescription does NOT support the administration of medication by subcutaneous infusion including via syringe drivers

Name:	Date of birth:	NHS No:
ALLERGIES/SENSITIVITIES:	WEIGHT (IF APPROPRIATE)	
Name of Prescriber (Print Name)	Contact Details of Prescriber	
Please complete all relevant section in BLOCK CAPITALS. Ensure instructions for administration are consistent with the anticipatory clinical plan. Doses must be written in whole numbers (e.g. 500 mg not 0.5 g and write micrograms in full not mcg). NB Consider opiate naïve patients.		

DATE	QUANTITY	MEDICATION	DOSE	CLINICAL INDICATION	ROUTE	FREQUENCY	PRESCRIBER
	x 10mg/1ml ampoules	MORPHINE SULPHATE		For pain or breathlessness	s/c bolus		
	2x 25 mg / ml	LEVOMEPROMAZINE	6.25 mg	For nausea or vomiting	s/c bolus		
	3x 10 mg / 2 ml	MIDAZOLAM	2.5-5 mg	For anxiety and agitation and restlessness	s/c bolus		
	2x 5 mg / ml	HALOPERIDOL	1.5-3 mg	For hallucinations and agitation	s/c bolus		
	3x 400 micrograms / ml	HYOSCINE HYDROBROMIDE	400 micrograms	For terminal secretions and "rattle"	s/c bolus		
	2x 10 ml	WATER FOR INJECTION			s/c bolus		

PRESCRIPTION
MEDICATION ADMINISTRATION RECORD

Date	Time	Name of Medication	Dose	Site	Batch Number	Expiry Date	Quantity remaining	Signature

Prescribing for specific conditions or situations

- Patients with significant renal impairment

https://rowcrofthospice.org.uk/wp-content/uploads/Prescribing-at-the-End-of-Life-for-Patients-with-Renal-Impairment-G1612-04.09.2020.pdf

- Patients with Parkinson's Disease

https://rowcrofthospice.org.uk/wp-content/uploads/End-of-Life-Care-in-Parkinsons-Disease.pdf

- Specific foreseeable problems: seizures or major haemorrhage
- Choice of opioid and dose

How to prescribe Just in Case bags

- Template with prepopulated medication ranges on – may need to adjust opioid dose/choice
- Prescribe and issue prescription (EPS/FP10)
- PMAR chart to go in bag/box
- Clarify collection of bag/box and medication (provide identification)
- Inform relevant agencies involved in the patient’s care
- Does this trigger TEP/ Palliative Care Register where you work and follow up arrangements?

Things to consider

- Clinical review after administration of drugs – should be within 24 hrs.
- PMAR incomplete and/or out of date
- The PMAR is in fact a MAR chart – it is not a prescription, rather a way of documenting administration of the prescribed medication
- Using JICB meds for a syringe pump
- Informal carer administration/delegation

Some Resources

1. S+W Devon Formulary – Chapter 16 Palliative Care

https://southwest.devonformularyguidance.nhs.uk/formulary/chapters/16.-palliative-care

2. N+E Devon Formulary – Chapter 16 Palliative Care

https://northeast.devonformularyguidance.nhs.uk/formulary/chapters/16-palliative-care

3. Rowcroft Hospice website – follow tabs How Can We Help, then Referrals, then Clinical Resources

https://www.rowcrofthospice.org.uk/how-we-can-help/referrals-access-services/clinical-resources/

4. St Luke's Hospice website – follow tabs Information Hub, then Healthcare Professionals

https://www.stlukes-hospice.org.uk/healthcare-professionals/

All above include links to the Devon Opioid Conversion Chart

Some Resources

5. NDDH Symptom Management in Palliative Care Guidelines:

https://www.northdevonhealth.nhs.uk/2019/11/symptom-management-in-palliative-care-guidelines/

6. Cornwall Hospice Care – you can visit the website then follow tabs Our Care, then Healthcare Professionals, then Professional Advice, then APG chart (takes you to this pdf document)

https://www.cornwallhospicecare.co.uk/wp-content/uploads/2019/04/APG-V7-FINAL-1.pdf

7. Palliative Care Adult Network Guidelines Plus; Dr Ian Back, Dr Max Watson, Dr Nigel Sykes, Dr Craig Gannon and Peter Armstrong

https://book.pallcare.info/

This online resource (and available as an App) includes an opioid dose converter and information about syringe pump medication compatibility

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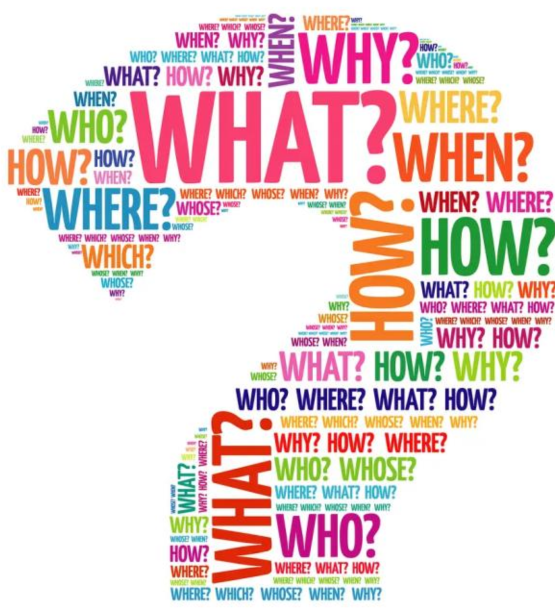

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