

**Palliative Care:
What, Who, When, How?**

Robert Twycross

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Palliative Care: What?

....an approach that improves the **quality of life** of patients and their families facing the problem 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**.

World Health Organization 2002

Palliative Care

- Focused on **quality of life**
- **Holistic** (physical, psychological, social, spiritual)
- Based on **need**, **not** limited by diagnosis or prognosis
- Applies at any stage, across all age groups

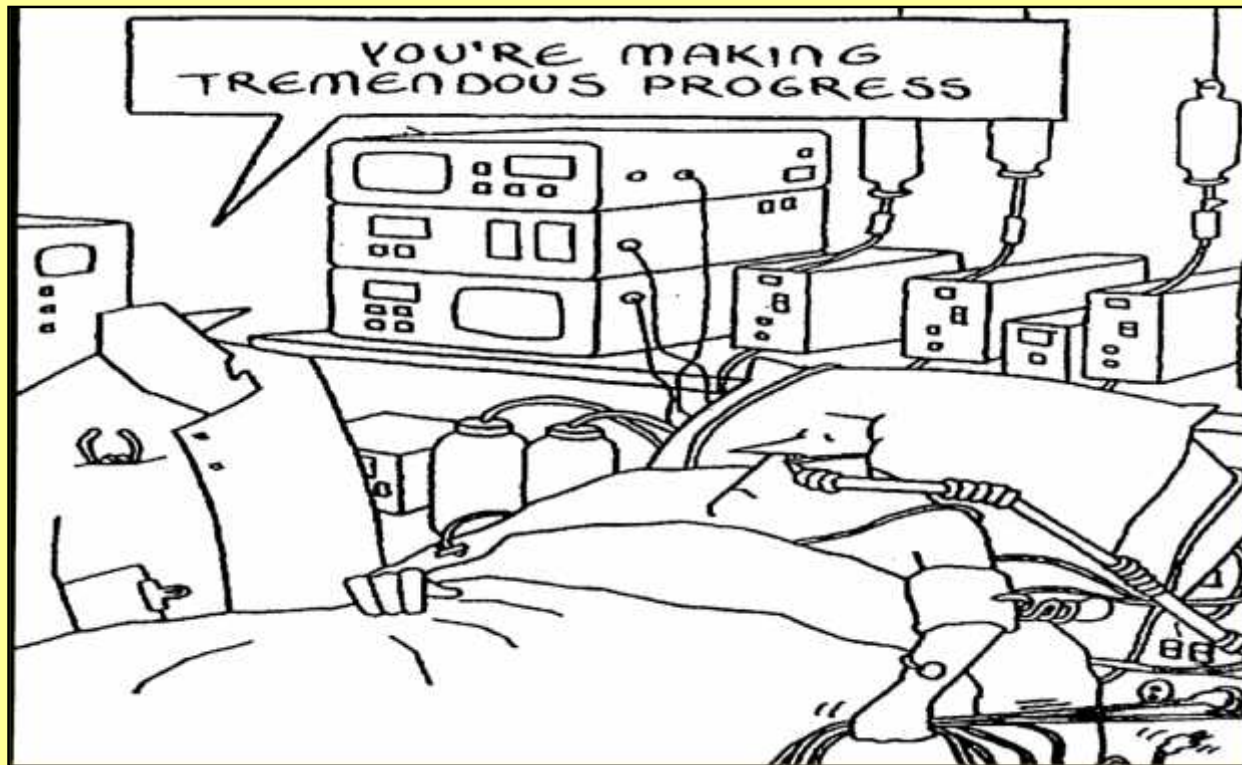
‘Care beyond Cure’



Holistic humane care for
human beings;
not mechanical care for
human machines

‘I want to be treated as a whole person’

Palliative Care: what it is not!



Quality, not quantity

Avoid ‘therapeutic obstinacy’

Preserve life when feasible
but allow natural death
when death is inevitable

Palliative Care: Who?

Country-specific:

palliative care tends to fill the gaps in existing provision for continuing care

UK: lymphoedema

Moldova: ostomy care

Moscow: post-stroke, long-term ventilation

Palliative Care: When?

‘Consider for any patient with
metastatic cancer
and/or high symptom burden’

Smith et al. 2012. (ASCO) J Clin Oncol 30: 880-887.

Essence of Palliative Care

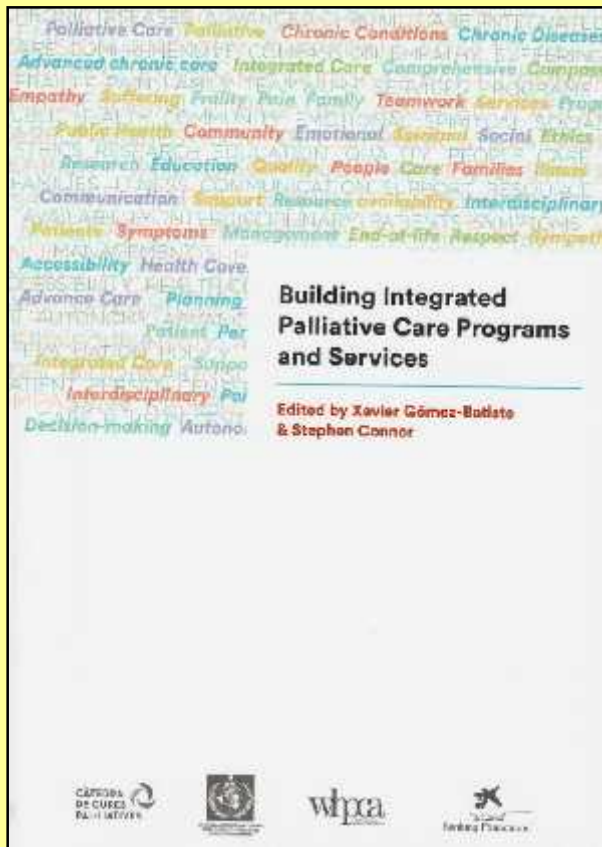
Helping people
make the difficult transition
from being seriously ill and fighting death
to being incurably ill and seeking peace

Palliative Care: How?

‘... the need for health services to provide **integrated palliative care** ...
in the context of
universal health coverage.’

World Health Assembly 2014

Palliative Care: How?



- Inpatients
- Outpatients
- Home care
- Day care
- Support teams
- Bereavement support

<https://www.thewhpc.org/resources>

How? Patients' Priorities

Effective communication,
shared decision-making

Expert care

Respectful and compassionate care

Trust and confidence in clinicians

Virdun et al. 2015 Pall Med 29:774-796

Relationship-Centred Care

- Authenticity
- Empathy
- Partnership
- Mutual benefit

Beach et al. 2006 J Gen Intern Med 21:S3-8.

‘Minimize formality; maximize humanity’

Relationship-Centred Care

Relationships are built on **trust**;
fostered by honesty, poisoned by deceit

How do you create trust?

Hello, my name is...



Dr Kate Granger

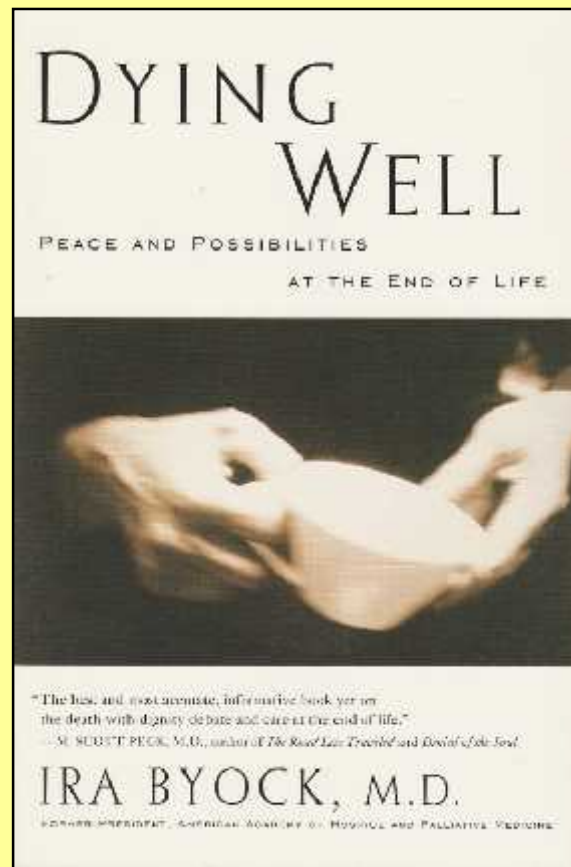
Introductions [make] a human connection...
They begin therapeutic relationships and can **instantly build trust** in difficult circumstances

Empathy

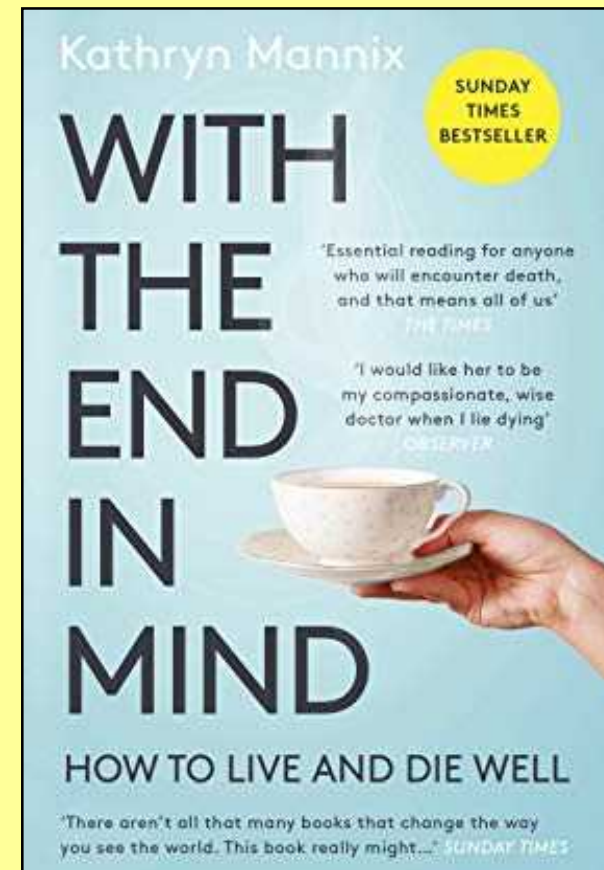
A cognitive ability to imagine
what someone else is feeling

Enhanced by listening to
people's stories

Patients' Stories



1996



2017

Empathy-based Care

Patients need empathy and understanding in order to express their preferences, values, and fears...

Hunink 2004 BMJ 329: 1051

Doctor-Centred Communication

‘Here are the facts and figures... these are the options [*surgery, radio-, chemo-therapy*]’

‘What do you want to do?’

- Options are overwhelming
- All sound terrifying
- Patient doesn't know what to do...
- **PANIC!!!**

What I need to know when talking to someone with advanced disease

- What do you understand about your illness?
- What are your concerns about the future?
- If your health were to get worse, what would you want to do in the time that's left?
- What trade-offs are you willing to make?
- How much suffering are you prepared to accept in order to gain added time?
- Who do you want to make decisions for you if you cannot?

Susan Block

Holistic Care takes Time!

Initial consultation:

median = 55 minutes [20–120]

- symptom management 20 [0–75]
- coping 15 [0–78]
- understanding 10 [0–35]

Jacobsen et al 2011. J Pall Med 14: 459–64

Warning!

‘If you start with the physical,
it is almost impossible to move
to the psychosocial’

Peter Maguire

‘Let the patient set the agenda...’

‘What do you hope will come out
of this consultation?’

‘How can I help you?’

‘What troubles you most?’

Dying Patients: Red Alerts

Pain *not* responding to your analgesia

Nausea/vomiting *not* responding to anti-emetics

Inoperable **bowel obstruction**

Constipation *not* responding to routine measures

Breathlessness at rest

Insomnia/nocturnal distress

Anyone expressing **distress** that they are dying

Anyone you think is dying badly

Who should we be teaching?

- All healthcare professionals
- All healthcare students
- Policy makers, general public

What should we be teaching?

1. Holistic relationship-centred care
2. Communication skills
3. Teamwork
4. Pain and symptom management
5. Attention to detail
6. Continuity of care
7. A sense of urgency
8. Ethics

Attention to detail

Ask ‘Why? Why? Why?’

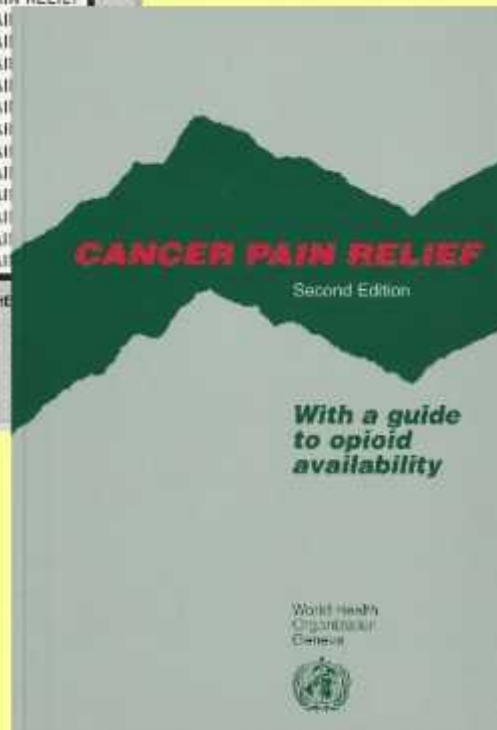
Do not make unwarranted assumptions

Make sure all the pieces of the jigsaw
puzzle fit together

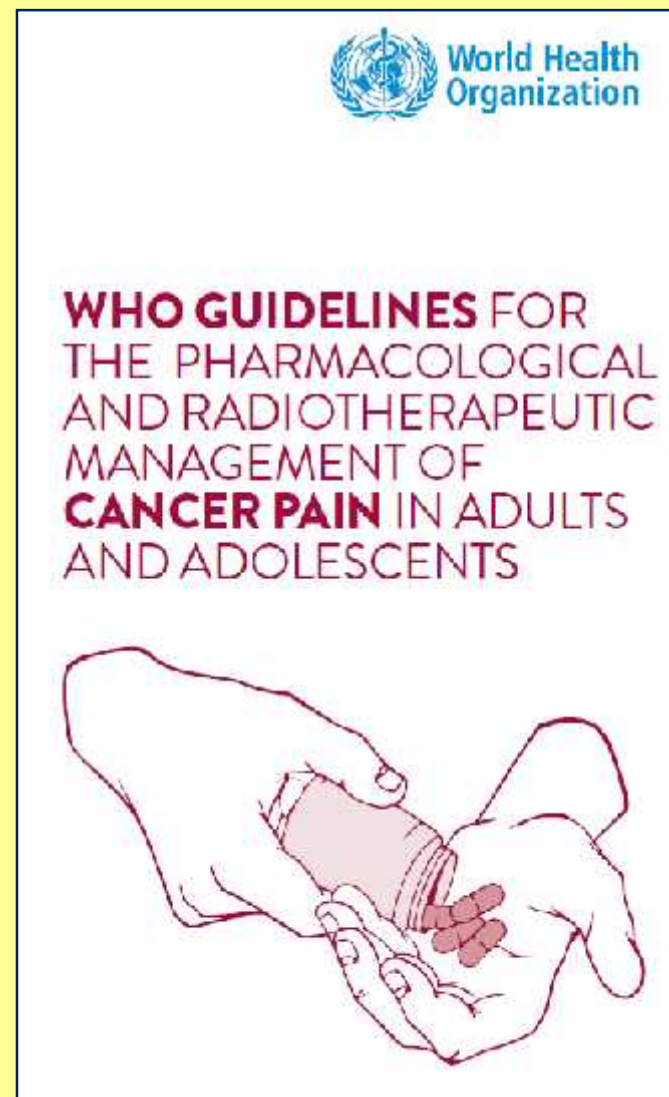
Individualize/fine-tune management



1986



1996



2018

WHO Principles of Analgesic Use

‘By the mouth’

‘By the clock’

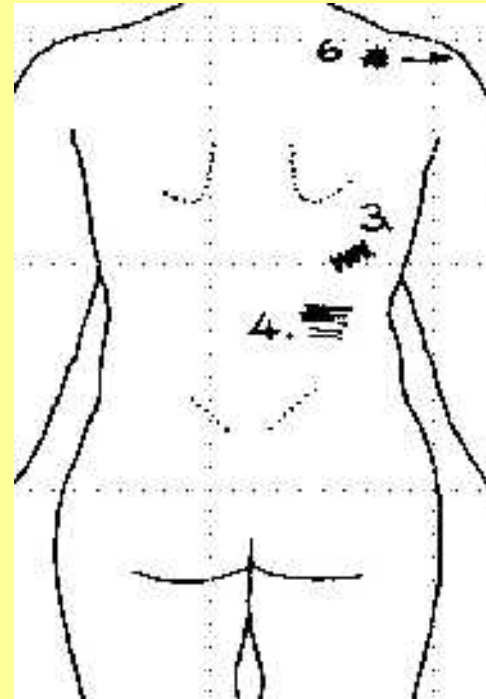
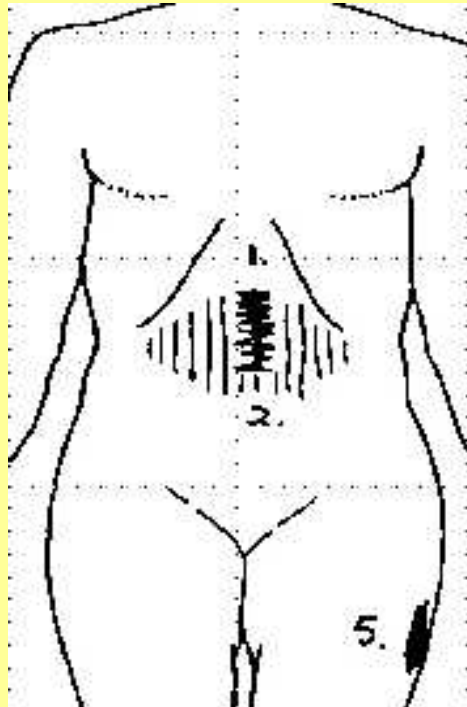
‘By the ladder’

‘Dose titration’

‘Adjuvant drugs’

The right drugs by the right route in the right
doses at the right time intervals

Woman (63): 10 days post-laparotomy



Distressed
Drowsy
Insomnia

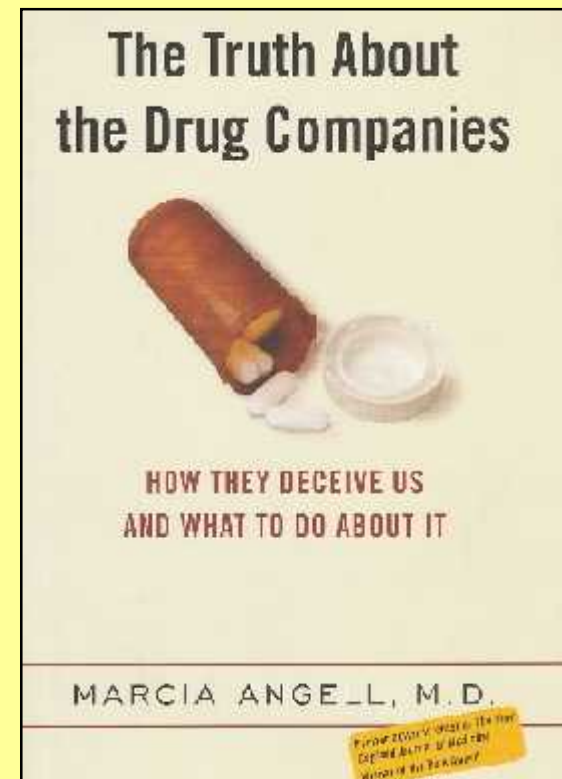
1. incision [sutures]
2. cancer? constipation?
3. fractured rib

4. muscle spasm
5. nerve compression
6. trigger point

Pharmaco-economics

Prescribe generic drugs

‘New’ does not mean
‘better’



2004

Lancet Commission on Global Access to Palliative Care

Knaul FM, Farmer PE, Krakauer EL et al.
Alleviating the access abyss in palliative care and pain
relief: an imperative of universal health coverage.

Lancet 2017

[http://dx.doi.org/10.1016/S0140-6736\(17\)32513-8](http://dx.doi.org/10.1016/S0140-6736(17)32513-8)

Essential Medicines

Amitriptyline

Bisacodyl (senna)

Dexamethasone

Diazepam

Diphenhydramine (chlorpheniramine or dimenhydrinate)

Fluconazole

Fluoxetine (sertraline and citalopram)

Furosemide

Hyoscine butylbromide

Haloperidol

Ibuprofen (naproxen, diclofenac, or meloxicam)

Essential Medicines

Lactulose (sorbitol or polyethylene glycol)

Loperamide

Metaclopramide

Metronidazole

Morphine

Naloxone

Omeprazole

Ondansetron

Oxygen

Paracetamol

Petroleum jelly

Underlying Systemic Values of Health 'Industry'

Competition, rationalism, productivity,
efficiency, and profit

Incompatible with compassion and
caring

Youngson & Blennerhassett, BMJ 2016;355:i6262

Incompatible Approaches

Biomedical Palliative care

Doctor

Boss

Partner

Focus

Disease

Patient

Goal

Cure

Comfort

Death

Failure

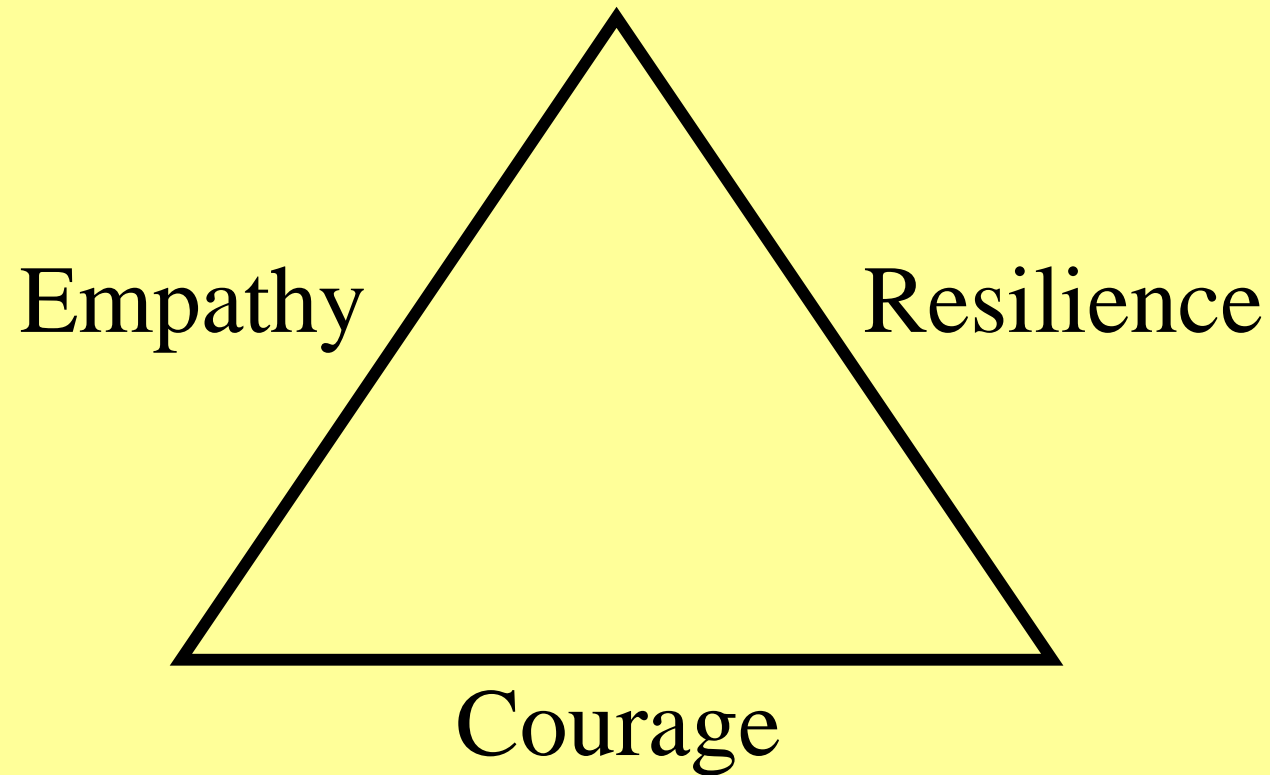
Accepted

Necessary Attitude

‘You matter because you are you.
You matter to the last moment of your life,
and we will do all we can
not only to help you die peacefully,
but to live until you die.’

Cicely Saunders

Necessary Attributes



Mary Baines

Teamwork

...is the fuel that allows
ordinary people to achieve
extraordinary results

Thank you for listening
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