

ADVANCE DIRECTIVES – DOES THE DOCTOR ALWAYS KNOW BEST?

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INTRODUCTION

Every day, doctors discuss with patients the options for their treatment. Some patients refuse further treatment or request limited treatment and we have to abide by that patient's decision, even if it seems irrational to us. Advance directives are a way of refusing certain medical interventions in advance, so that when a patient is mentally incapable or unable to communicate his views his previous wishes will be respected. Advance directives are not "voluntary euthanasia" or "assisted suicide". They are an expression of a patient's future wishes. A living will relates to medical treatment and the only similarity it has to an ordinary will is that if it is not drawn up properly it can cause a lot of problems, may be invalid and may not fulfil the person's wishes.

In this article I have attempted to outline the practicalities of drawing up and implementing an advance statement (living will) and also discuss the advantages and disadvantages.

THE PRESENT LEGAL SITUATION

A competent adult has the right to refuse medical intervention for any reason. Patients and their relatives cannot demand inappropriate or futile treatment. The current legal position in the UK is such that, in the absence of any advance directive refusing treatment, a patient who is unable to discuss or consent should be treated in his "best interests". It is left for the doctor to decide what the patient's best interests might be. The doctor's decision should take account of the clinical situation and also the past and present feelings of the individual, the latter often being ascertained from relatives or carers. In England, Wales and Northern Ireland there is at present no legal mechanism for nominating a proxy to make treatment decisions on your behalf. Relatives and next of kin have no legal power to consent on behalf of a person who is incapacitated but in Scotland a tutor or proxy can be nominated to make decisions on a patient's behalf. (A person can, of course, legally nominate in advance, someone to deal with their financial affairs once they lack capacity giving Enduring Power of Attorney.)

In the majority of situations the "best interests" decision is straightforward but sometimes we have no way of ascertaining an incapacitated person's previous wishes about life-sustaining treatment or there is conflicting advice from relatives.

ADVANCE DIRECTIVES – ALREADY IN USE

Advance directives are not new. The medical profession has always recorded patients' views and, I hope, abided by their

wishes. It is part of good medical practice to discuss the prognosis and the possible future course of an illness with a patient. Some are keen to discuss their future care. One patient of mine has written in indelible pen across his chest "DO NOT RESUSCITATE" and regularly updates his decision! On each admission his "advance directive" is discussed and recorded in a more conventional way in his notes. He is not depressed, has no major irreversible underlying condition but is adamant he does not wish to receive cardiopulmonary resuscitation. Another patient with motor neurone disease when asked about her wishes with regard to resuscitation and life sustaining treatments if the need arose said "Over my dead body". Her words and the ensuing discussion were recorded in her notes and when she deteriorated and couldn't communicate easily, her decision was already clear. It probably didn't affect the treatment decision but her family and carers were satisfied that things had been as she wanted.

Many people have no opportunity to discuss the course of a future illness with their doctor or relatives as it comes unexpectedly through sudden illness or accident. A carefully worded formal advance directive or statement is the next best thing to a discussion and decision.

WHAT IS A LIVING WILL, ADVANCE STATEMENT OR ADVANCE DIRECTIVE?

An *advance statement* (also known as a living will) can be a written document, a witnessed oral statement, a signed printed card (Fig 1) or a note of a discussion recorded in a patient's file. Casual remarks made in ordinary conversation to friends or relatives such as "If I ever get like that I would rather be dead" cannot carry any legal weight but could contribute to the evaluation of a patient's previous wishes⁽¹⁾. An advance statement covers treatment choices only when a patient lacks mental capacity and can be of various types.

- 1 It can be a *requesting statement* reflecting an individual's aspirations and preferences. It is a guide for health professionals but does not bind them if it conflicts with professional judgement.
- 2 It can be a *statement of general beliefs* about aspects of life which an individual values. It makes no specific request or refusal but attempts to give a biographical portrait of the individual as an aid to decision making.
- 3 It can be a *statement which names another person* who should be consulted at the time a decision is to be made. This can supplement the scope of a written statement. However the views of the proxy are presently not legally binding in England, Wales and Northern Ireland.

MEDICAL EMERGENCY CARD
 supplied by
VOLUNTARY EUTHANASIA SOCIETY
 13 Prince of Wales Terrace London W8 5PG 0171 937 7770

My Full Name is

If there is no reasonable prospect of recovery I do NOT wish to be resuscitated or my life to be artificially prolonged
 My Advance Directive is lodged with

1. Medical Information eg. blood group

2. After my death my organs may be used for medical purposes

3. Next of Kin

Signature Date

Fig 1 – Medical Emergency Card as supplied by Voluntary Euthanasia Society.

- It can be a clear instruction refusing some or all medical procedures – this is an *advance directive*. If this is made by a competent adult it does have legal force if it covers a particular situation and treatment. It may be a formal written witnessed statement or it may be a record of a discussion written in a patient's notes, for example regarding cardiopulmonary resuscitation.
- It can be a statement which *specifies a degree of irreversible deterioration*, such as severe dementia, after which no life-sustaining treatment should be given. This also has legal force.
- It can be a *combination* of the above.

Advance statements and directives are only applicable when a patient is mentally or physically unable to communicate his wishes. Written statements do not carry more weight than a competent contemporaneous decision. Children cannot make an advance directive but their oral or written views should be taken into consideration.

HOW DOES SOMEONE PRODUCE AN ADVANCE STATEMENT?

The minimum information required (as suggested by the BMA guidelines⁽²⁾) is listed in Figure 2. A lawyer is not required and a doctor's signature as a witness is not mandatory but if there is a future debate about a person's mental capacity a medical witness is helpful. The Voluntary Euthanasia Society and the Terrence Higgins Trust both produce a pack for people wishing to make advance directives (Fig 3). There are clear explanatory notes, appropriate forms and also advice about regular updating of forms. The forms produced by the Terrence Higgins Trust are

THIS IS THE MINIMUM INFORMATION SUGGESTED IN DRAWING UP AN ADVANCE STATEMENT

- Full name
- Address
- Name and address of general practitioner
- Whether advice was sought from health professionals
- Signature
- Date drafted and renewed
- Witness signature
- A clear statement of your wishes, either general or specific
- The name, address and telephone number of your nominated person, if you have one.

Fig 2 – Checklist for writing an advance statement.

specifically for patients with HIV infection but could be used by anyone. The form produced by the Voluntary Euthanasia Society is shown in Figure 4. Age Concern may seem to be a more acceptable source of advice for some patients, but in fact their advice is to provide the information as in Figure 3.

Advance directives (information and forms) are available from:

Voluntary Euthanasia Society, 13 Prince of Wales Terrace, London W8 5PG. Tel 0171-937-7770. £2 for three copies and set of notes £1 for Emergency Medical Card

and

Terrence Higgins Trust, 52-54 Grays Inn Road, London WC1X 8JU .Tel 0171-831-0330. One copy free to HIV positive individuals. Otherwise 34p per copy.

Fig 3.

DOCTORS WITNESSING ADVANCE DIRECTIVES

This is a guide for doctors advising about or witnessing an advance directive.

- Patient must be over 18 years of age.
- Is the patient mentally competent? (The High Court has held that a person has capacity if he can understand and retain the information relevant to the decision in question, can believe that information and can weigh that information in the balance to arrive at a choice.) A patient detained under the Mental Health Act 1983 cannot make an advance directive covering treatment of their mental state, but may be able to decide on physical treatment.
- Discuss the patient's reason for making a directive and advise against a hasty decision particularly if they have just received bad news. Ensure they are not under the undue influence of another person.
- Does the patient understand the purpose of the directive?
- Ask him to discuss the directive with his next of kin if possible.
- Advise about the minimum information which is required and the standard formats available.

ADVANCE DIRECTIVE

TO MY FAMILY, MY PHYSICIAN AND ALL OTHER PERSONS CONCERNED
THIS DIRECTIVE is made by me (full name in capitals) _____
of (address) _____
at a time when I am of sound mind and after careful consideration.

I DECLARE that if at any time the following circumstances exist, namely:

- (1) I suffer from one or more of the conditions mentioned in the schedule; and
- (2) I have become unable to participate effectively in decisions about my medical care; and
- (3) two independent physicians (one a consultant) are of the opinion that I am unlikely to recover from illness or impairment involving severe distress or incapacity for rational existence.

THEN AND IN THOSE CIRCUMSTANCES my directions are as follows:

- 1 that I am not to be subjected to any medical intervention or treatment aimed at prolonging or sustaining my life;
- 2 that any distressing symptoms (including any caused by lack of food or fluid) are to be fully controlled by appropriate analgesic or other treatment, even though that treatment may shorten my life.

I consent to anything proposed to be done or omitted in compliance with the directions expressed above and absolve my medical attendants from any civil liability arising out of such acts or omissions.

I wish it to be understood that I fear degeneration and indignity far more than I fear death. I ask that my medical attendants and any person consulted by them to bear this statement in mind when considering what my intentions would be in any uncertain situation.

I RESERVE the right to revoke this DIRECTIVE at any time, but unless I do so it should be taken to represent my continuing directions.

SCHEDULE

- A Advanced disseminated malignant disease.
- B Severe immune deficiency.
- C Advanced degenerative disease of the nervous system.
- D Severe and lasting brain damage due to injury, stroke, disease or other cause.
- E Senile or pre-senile dementia, whether Alzheimer's, multi-infarct or other.
- F Any other condition of comparable gravity.

*I nominate (name in capitals) _____
of (address) _____
(tel. no.) _____
as a person to be consulted by my medical attendants when considering what my intentions would be in any uncertain situation.
*Delete if not applicable.

My General Practitioner is (name of GP) _____
of (address) _____
(tel. no.) _____
*Before signing this directive I talked it over with my GP.
*Delete if not applicable.

Signed _____
Date _____

WE TESTIFY that the maker of this Directive signed it in our presence, and made it clear to us that he/she understood what it meant. We do not know of any pressure being brought on him/her to make such a directive and we believe it was made by his/her own wish. So far as we are aware we do not stand to gain from his/her death.

Witnessed by:
Signature: _____ Name: _____
Signature: _____ Name: _____
Address: _____ Address: _____

This Directive was reviewed and confirmed by me on the following dates (sign your name each time you enter a date).

© Voluntary Euthanasia Society, 13 Prince of Wales Terrace, London W8 5PG, 1995

Fig 4 – Advance directive as supplied by Voluntary Euthanasia Society

- 7 Discuss the likely progress of any current illness so that the patient can make the directive as specific as possible.
- 8 Strongly suggest the patient should not refuse all medical treatment, allowing symptomatic treatment including antibiotic treatment of urinary tract infections and basic nursing care.
- 9 If the patient is on longterm life-sustaining medication, for example thyroxine, insulin, or treatment for angina, suggest that he should make particular reference as to whether and in what circumstances these should be withheld.
- 10 Advise a woman of childbearing age that her directive would probably be invalid if she is pregnant with a viable foetus.
- 11 Advise that a doctor and another witness should witness the signature. (One or two witnesses except relatives or those likely to gain financially from the death of the person are acceptable, but a medical witness who knows the person well is useful in case of future dispute about a patient's competence.)
- 12 Ask him to make at least two copies and lodge them in his private papers (and inform his next of kin of its whereabouts), in the GP notes and if relevant, in hospital records.
- 13 Advise him that the directive can be revoked at any time. (All copies should be destroyed).
- 14 Advise him to update the directive to make it as specific as possible if a new medical condition occurs.
- 15 Advise regular review of the directive with a new date and signature preferably every two years at least.

IMPLEMENTATION OF ADVANCE DIRECTIVES

An advance statement or directive relates to the care of a patient in any location, not just hospitals. It is the person's responsibility to ensure that the directive is lodged with his GP and that his next of kin or carers are aware of its existence. A directive is legally binding if it is a clear refusal of a particular treatment in a specific situation.

In an emergency the principle of necessity allows health staff to provide treatment without consent. In an emergency staff would be covered by their Common Law Duty of Care so can treat without consent. This includes the restraint of a person medically and physically if they are likely to commit harm. Delaying emergency treatment in Casualty whilst carefully checking a complicated directive would be unacceptable. If, however, a patient in hospital has specifically declined resuscitation and there is either a formal written directive, or an oral statement recorded in the hospital notes, this is legally binding, and should be respected. If a patient is treated against his express wishes he could take legal action for trespass. A court would, however, take a lenient view in such a situation as by definition emergency treatment is provided in the heat of the moment. Figure 5 attempts to clarify the situation and provide a quick reference.

In a non-emergency situation there is more time to consider the situation and study an advance statement or directive and come to a decision. A patient detained under the Mental Health Act cannot refuse treatment of their mental condition but in some circumstances can decline physical treatment either at the time or in advance. Although the law is not clear, the BMA guidelines suggest a person should not be able to refuse in advance appropriate basic nursing or medical care aimed at alleviating distress or preventing a public health

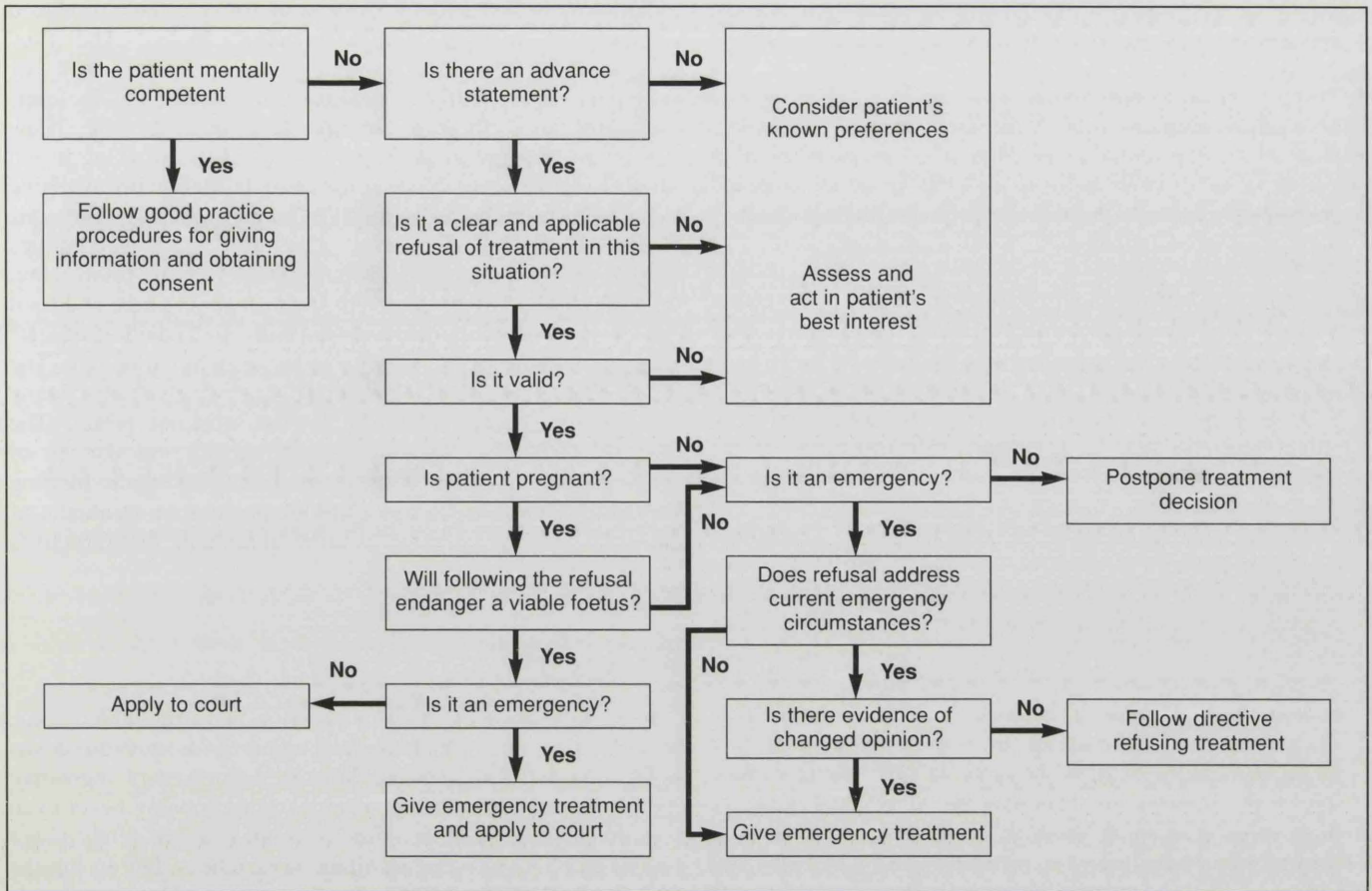


Fig 5 – Implementation of advance directive in an emergency situation.

hazard. A patient (or his relative) cannot demand inappropriate or futile treatment either at the time or in advance.

In a non-emergency situation, advance directives may involve the withholding of antibiotics from a patient with pneumonia or the withholding of invasive methods of nutrition including gastrostomy, nasogastric or intravenous feeding. Patients in a **persistent vegetative state** where there is no chance of recovery, but whose life is dependent on artificial feeding are a special case. Diagnosis of the condition can only be made after twelve months when it is due to head injury but six months if it is due to other causes. The courts must be consulted before treatment is withdrawn so any directive relating to a patient in a persistent vegetative state must be put before the courts.

If doubt exists about what the individual intends, the law supports the presumption of providing clinically appropriate treatment.

ADVANTAGES OF ADVANCE DIRECTIVES

- Discussion of a statement or directive clarifies the patient's choice and even though a formal directive refusing treatment may not be produced a statement or recorded discussion in the medical notes may give a patient peace of mind.
- Advance directives remove the burden of choice from the health professionals and also the patient's relatives. Even though relatives don't make the final treatment decision a feeling of guilt can add to the distress at the time of a relative's death.
- Many relatives are unclear what the patient's wishes might

be particularly when the relative is not a spouse. Although advance statements are not perfect they may be the best substitute for contemporaneous consent or refusal.

DISADVANTAGES OF ADVANCE DIRECTIVES

- The main disadvantage of advance directives is the difficulty of producing a statement which relates to the particular clinical situation. The development of disease-specific directives may be the way forward⁽⁹⁾.
- No-one knows how they will adapt to a particular disability until it happens and a person's decision about what quality of life is acceptable may well change with illness or severe disability. Does a doctor or relative have any better idea about how a patient will feel or adapt?
- A patient may be denied appropriate treatment in the event of misdiagnosis. The Voluntary Euthanasia Society format seeks to avoid this by requiring at least two doctors to be involved in the assessment of the patient.
- Unforeseen treatments may in the future allow treatment of what today seems to be an irreversible neurological condition and the patient in the meantime may be denied life-sustaining treatment and not be alive to benefit from a cure. It is, however, perhaps naïve to think that patients with advanced neurological disease would be cured by a new treatment once severe structural damage has occurred. If a cure for what previously seemed an incurable condition did become available, a patient's directive in most cases would not be applicable, as most directives specify a non-treatment decision only in the situation of irreversible or terminal conditions. In the case of a patient who made a blanket non-treatment decision after diagnosis

of an illness which subsequently became treatable an application to the Court would be appropriate.

- There is always concern that unscrupulous relatives may pressurise someone to make an advance directive. However in the absence of a directive the same relatives may be asked by the doctor to give advice on the patient's previously expressed wishes to enable the doctor to act in the patient's "best interests".
- Patients may change their mind but forget to revoke a directive and therefore be deprived of treatment. It may also be difficult in a patient with dementia to know when they are competent to revoke a directive. Some directives will be badly drafted and unclear but in the case of uncertainty the law stands firmly on treatment in the patient's best interests.
- Some opponents of advance directives are concerned particularly that the elderly who present with multiple diagnoses and complex problems may be denied appropriate treatment and rehabilitation if they have made a directive. Ironically, they could, therefore, become more disabled (for instance with pressure sores due to the combination of untreated incontinence and immobility). The treatment of incontinence and appropriate nursing care of the disabled should not be excluded by a well worded directive. These arguments do not show that advance directives are a bad idea; rather, they suggest instead that a carefully-worded directive, possibly using a standard format with opportunities for more specific requests, is appropriate.

WHO MAKES AN ADVANCE STATEMENT?

There is no research in the UK looking at who has made an advance statement or directive. In America the Patient Self-Determination Act of 1990 stated that all hospitals and nursing homes receiving reimbursement from Medicare or Medicaid must inform patients on admission of their right to execute an advance directive. Research looking at who made directives⁽⁴⁾ showed that people were more likely to make one if they had been admitted to hospital twice in the preceding year. Those who had made an ordinary will were also more likely to make an advance directive. Interestingly, there was no correlation between formal or informal advance care planning and age, sex, income, mental status, education, religious beliefs or self-perceived health status. Five months after the implementation of the act there was no significant increase in formal advance directives although there was a significant increase in the number of patients discussing end of life issues with their proxies.

It seems that media coverage of cases such as the Cruzan case in America and the Bland case in the UK are more likely than legislation to produce an increase in directives.

PROPOSED LEGISLATION

There is no doubt that the law on advance directives needs further clarification. They can, as already discussed, be legally binding but are covered only by common law. The House of Lords Select Committee report on medical ethics supported the development of advance directives but concluded that legislation was unnecessary, suggesting that colleges and faculties of all healthcare professions should jointly develop a code of practice to guide their members.

The BMA with the Royal College of Nursing have produced a code of practice with explanatory notes. The Law Commission, however, recommended there should be a law to cover living wills⁽⁵⁾. The government set up an inter-departmental working group to consider the Law Commission's proposal. The outcome of the working group and the government's response will probably be available soon (probably by the time this article appears). The Law Commission raised many questions and uncertainties including the validity of chance remarks about future care, whether refusal of all treatment such as nursing care and food and water could be included, and the legal position of staff who do not accept the validity of the patient's directive. The Law Commission has produced draft legislation. Many groups have been consulted by the working group. The British Geriatrics Society warned against the danger of advance directives but as they can already be legally binding it would seem sensible to clarify the position on treatment of mentally incapacitated adults rather than hope that directives will go away.

DISCUSSION

The Bland case⁽⁶⁾ provoked discussion and highlighted some of the dilemmas which people making advance directives seek to avoid. Tony Bland, who was in a persistent vegetative state after the Hillsborough disaster, had probably never even contemplated an advance directive and had apparently never expressed his views on his future preferences, but during the Airedale NHS Trust v Bland judgement the House of Lords took the opportunity to state that advance refusals of treatment even if they result in death could be legally binding if expressed as clear instructions. There was also a clear decision that "invasive methods" of feeding are a medical treatment and not part of basic care.

The frequent remarks made by relatives, friends and carers about the poor quality of life of certain patients with advanced dementia and neurological disease suggest that many of us fear being in a similar rather degrading situation. The response is to try to give as high quality care as possible for the elderly and disabled, but is it enough? New drugs and technology have increased the life-sustaining treatments available and the elderly and disabled have certainly benefitted from these advances. However a small proportion of patients are very disabled often both mentally and physically and cannot communicate their wishes. Should a patient with a severe stroke, inability to swallow, speak or stand, have gastrostomy feeding on a long term basis and courses of antibiotics for recurrent chest infections? Some would say yes, some would say it's not fair on the patient. We don't know what he wants as he cannot communicate his wishes or comprehend the complex arguments involved. His family feel his best interests are served by prolonging his life as long as possible. In the past the patient would have a nasogastric tube which he could pull out if he wished to do so. A gastrostomy tube is much more difficult to remove and is an access route for antibiotics. Some would say the doctor must make a decision in the patient's best interests, but what are they?

Patients at home or in care being treated by their GP have an advantage as the GP who has cared for the patient, perhaps over many years, will already know the patient's background and any previously expressed preferences. It is important that any knowledge of the patient's previous preferences or of any advance directive is passed on to the hospital if admission is necessary.

Should a patient with advanced dementia receive antibiotics for a lobar pneumonia? Who or what is the old person's friend: the relative requesting antibiotics, the doctor who gives or withholds antibiotics, or the patient's advance directive?

Those who oppose advance directives must consider how they would like to be treated in the above situations, and then ask whether their close relatives know what they want and would they all agree? The next question is how would they treat such a patient? Surely an advance directive or statement would be helpful whatever the answers. It may be easier to pass such a patient or such a difficult decision on to the doctor who cares for that patient in the long term, whether at home, in hospital or in a residential or nursing home.

I'm not suggesting everyone would wish to produce an advance directive or statement. Many people don't make an ordinary will and the majority don't execute an Enduring Power of Attorney in case of mental incapacity. Developments in medicine are a marvellous thing: we can cure more illnesses, alleviate nearly all pain but we can't alleviate all suffering, even with excellent nursing, and we certainly can't always predict how each patient will want to be treated. We can strive to act always in the patient's best interest but can't we let advance directives and statements give us a helping hand?

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