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POST-COMA UNRESPONSIVENESS AND MINIMALLY RESPONSIVE STATE

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A GUIDE FOR FAMILIES AND CARERS OF PEOPLE WITH PROFOUND BRAIN DAMAGE

This booklet is based on Ethical Guidelines for the Care of People in Post-Coma Unresponsiveness (Vegetative State) or a Minimally Responsive State, developed by the National Health and Medical Research Council in 2008

WORKING TO BUILD A HEALTHY AUSTRALIA

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This guide has been prepared for the families and friends of someone diagnosed as being in a state of post-coma unresponsiveness (PCU) or a minimally responsive state (MRS).

It describes these conditions and the types of treatment and care that may, or may not, apply in individual situations. It also explains the ethical guidelines that have been prepared for health professionals who are in involved in making decisions about the care of your family member or friend.

Throughout the journey with your family member or friend in PCU or MRS, you may experience many different feelings – sadness, anger, pity, blame, hope, denial, guilt, depression, love, anxiety, panic, frustration, helplessness, hopelessness. There can also be some very positive aspects to caring, often at the same time as the less positive ones.

We all respond differently, and all of these feelings are quite normal. There is no right or wrong way to react, and there are no right or wrong thoughts or feelings.

1 ABOUT PCU AND MRS

WHAT IS 'POST-COMA UNRESPONSIVENESS'?

After being in coma, a small number of people move into a 'twilight zone'. They appear to sleep and wake normally, but when they are awake, they show no sign that they are aware of things or people around them. They do not speak or respond in any way.

This is post-coma unresponsiveness, or PCU. Doctors will not make a diagnosis of PCU until the person has been in this state for at least four weeks after emerging from coma.

WHY NOT 'PERSISTENT VEGETATIVE STATE (PVS)'?

PCU has been called 'vegetative state' or 'persistent vegetative state'.

The term 'post-coma unresponsiveness', however, better describes this unresponsive state. It avoids the word 'vegetative' and makes no assumptions about awareness. It also avoids 'persistent', and so makes no assumptions about how long the person will remain unresponsive.

> It was clear that the only certainty regarding my son's condition was that his future was unknown.

HOW IS PCU DIFFERENT FROM COMA?

Coma looks like very deep sleep, but sleep from which the person cannot be roused in any way—not even in response to pain. It's assumed that a person in coma is deeply unconscious (though there is no way of 'measuring' consciousness).

People in PCU also show no responses, but appear to have periods of sleeping and waking.

Both coma and PCU can be caused by head injuries, illnesses, or the brain being deprived of oxygen (for example, following a drug overdose or heart attack).

IS A PERSON IN PCU BRAIN DEAD?

Coma and PCU are both quite different from brain death. A person in coma or PCU is still alive. Brain death, on the other hand, means that the person has died because all brain function has stopped permanently (even though the heart may keep beating for a time, as breathing can be kept going artificially by a ventilator).

IS A PERSON IN PCU AWARE OF WHAT'S HAPPENING?

Probably not. If someone is not responding at all, it's very unlikely that they are aware of the world around them. But we can never be absolutely certain.

This makes it important that everyone—family and friends, carers, health care staff—behave as if the person might have some awareness. Chat to the person, explain what's happening, involve him or her in conversations around the bed—and don't say things you would not want the person to hear, or things you think might be distressing.

Some people in PCU may move their face or body. Sometimes it may be the first signs of a response but it is difficult to be sure and it could simply be a reflex movement. What these movements mean could become clearer over time.

Sometimes the person will grimace or even moan. This may not be due to pain. If it is thought the person may be in pain, pain relief could be tried. If you are concerned, talk to the health care team.

For months after her car accident, Kelly was in MRS and her only reaction was to shrink away from pain—no other responses, no sounds. Then, while she was being bathed each day, she started to make moaning noises. The nurses thought it was pain. The doctor put her on medication to help, and increased it when the moaning got worse and her body seemed so tense.

Then one day the speech therapist said, 'good morning Kelly—and she said 'g'morning'. She'd been trying to talk. Gradually, as more words came, her moaning stopped and her whole body relaxed.

WHAT IS 'MINIMALLY RESPONSIVE STATE'?

Following coma or PCU, some people may start to show small and often inconsistent signs that they are aware of the world around them. This is described as minimally responsive state, or MRS. The person might, for example, say a word or two, or be able to move a finger or blink when asked to.

Responses might be very slow, and it can be difficult to be sure that it actually is a response, not just a random movement or sound. Family, friends and staff may need to spend lots of time with the person before they can be sure that responses are consistent. Even then, this can be misleading—it is easy to see what you hope to see—but families and close friends are often the first people to see a real response from the person.

WHAT ARE THE CHANCES OF IMPROVEMENT?

Some people in PCU may start to respond and move into MRS within the first six to twelve months, however there have been very rare instances where response has started some years later. Very rarely, people in MRS gradually gain a little speech and movement. But most people remain in PCU for the rest of their lives, with no sign of any response or improvement.

The longer a person is in PCU or MRS, the less likely it is that they will recover to a level where they can communicate with others.

Any improvement, if it occurs, will probably be very slow. The person will not recover completely. A few people recover limited ability to communicate, but almost never become independent in daily activities.

If there is going to be any significant recovery, studies and experience indicate that the chances are much greater in the first year. After this, improvement is less likely, though a few people will continue to make small gains over years.

Improvement is less likely if the brain damage is from lack of oxygen to the brain (eg, drug overdose, near-drowning), rather than from trauma (eg, a blow to the head). This is because lack of oxygen is more damaging to the brain.

It can be very difficult to strike a balance between hope and acceptance, and to keep despair at bay. Celebrate every tiny gain—but try not to build false hopes on them.

2 CARING FOR A PERSON IN PCU OR MRS

A person with severe brain damage is usually taken first to hospital and cared for in an Intensive Care Unit. The person will probably be in a deep coma, and will need various life support systems, including tubes inserted for breathing ('ventilation'), medications ('intravenous') and feeding ('feeding tube').

This hospital care is known as 'acute care'. It may take some weeks or months for a person's condition to stabilise, and he or she will remain in hospital throughout this time.

It's usually not until several weeks after the person has emerged from coma that PCU or MRS will be diagnosed. It's clear by this stage that any further improvement—if it occurs at all—will be very slow and probably very limited.

At this point, decisions need to be made about where ongoing care and treatment for the person in PCU or MRS will be provided, what form that care will take, and whether intensive treatment should be continued or scaled down.

These decisions are made by the health care team—doctors, nurses and allied health staff—after consultation with the family.

You can expect that the health care team will recognise the importance of families, and understand that families include those people who are closest to the person in knowledge, care and affection. This may be wider than the immediate biological family, and include those related by marriage and others whom the person sees or has chosen as his or her family (see the definition of 'family' in the glossary, page 29).

> After 13 months of inadequate hospital care, Sam (in MRS) had severe muscle contractures. I moved interstate so he could access slow stream rehabilitation. It has made an enormous difference to his comfort and quality of life.
>
> A year later, his tracheostomy tube has been removed (I was told he would have it for life) and his whole body is more relaxed. He can sit in a wheelchair, so I can take him out. He tries to assist with therapy. Personal care is much easier, he turns his eyes and head on command, he is beginning to use sounds to signal distress, and it's hoped he may soon be able to swallow some soft food.

WHERE IS A PERSON IN PCU OR MRS CARED FOR?

When a person in PCU or MRS leaves hospital, he or she may move to residential care (a nursing home), supported community care, or home to the care of family. Some may receive rehabilitation therapy in a nursing home. A few people in MRS may move to a rehabilitation hospital. However, these options may not all be available in some areas.

Following Greg's accident, he was admitted to a rehabilitation hospital and for some months had regular physio, occupational therapy and speech therapy. There was no improvement, no sign of any response, and therapy dropped back to a maintenance level.

His family wanted him to move to a community house—difficult because he could still not breathe without a tracheostomy, but the hospital found him a place. They trained both family and community house staff to manage his airway, and brought in the district nursing service to oversee his care. He's settled now in the community house and his family often take him out in the wheelchair (along with his portable suction pump).

Wherever it is provided, you can expect care to:

- maintain the person, make the most of any improvement, and prevent further health problems;
- provide an environment where the person is respected and supported socially, emotionally and spiritually as well as physically; and
- support the family physically, socially, emotionally and spiritually.

REHABILITATION

People in PCU or MRS may benefit from some rehabilitation therapy to make the most of any very slow improvement.

If available, rehabilitation therapy for people in PCU or MRS can be in a specialist rehabilitation hospital, in residential care (a nursing home), or in the person's or carer's home. Most rehabilitation hospitals cater for people who are expected to return to independent living after an illness or accident. They are rarely able to provide care for people in PCU or MRS.

For a person in PCU or MRS, rehabilitation therapy has three main aims:

- to monitor the person for any neurological (brain) change, and help them to build on any improvement that occurs;
- to prevent any new problems from arising—a particular risk with people who are dependent and cannot move; and
- to help families understand the person's prospects in the long term.

Rehabilitation therapy may involve:

- specialist medical care, to prevent and/or manage any distressing symptoms or complications, including infections and pain;
- nursing care for hygiene, to prevent bedsores, and to manage feeding tubes and pain;
- physiotherapy to keep the lungs clear, improve posture, and prevent muscle tightness and joint damage that can 'lock' limbs (eg, contractures);
- occupational therapy to assess the person for possible splinting or aids and equipment to help carers, and to watch for and build on any responses;

- speech pathology to assess swallowing problems, and build on any returning ability to communicate (through speech or body movements);
- dietitians to manage the person's diet;
- a range of non-medical approaches such as music therapy, diversional therapy, massage, recreation therapy, spiritual care; and
- clinical psychologists, and social workers to support families with counselling and access to other resources and care options.

Families and carers may be a valuable part of the rehabilitation team and in the longer term, therapists can often teach them to provide some ongoing therapy.

It's important for the health care team and the family to be clear about what the rehabilitation program, or a particular treatment, hopes to achieve, and what its limits are.

If treatment goals are not being met, or a treatment is too great a burden to the person—if its disadvantages outweigh the possible benefits—it's time to consider changes.

It might mean moving to a less intense level of therapy. When this happens, the person may slip back a little. It's important to understand that this is because therapy may have temporary effects that cannot be sustained as long-term benefits for the person.

MAINTENANCE CARE

Every person in PCU or MRS will need to be supported in the long term. Maintenance care usually includes:

- hygiene and steps to prevent bed sores;
- feeding through a tube (known as 'artificial nutrition and hydration' or 'ANH');
- some physical therapy to maintain muscle tone and prevent tightness and joint damage that can 'lock' limbs (eg, contractures); and
- treatment for infections and any distressing symptoms.

Some people in PCU or MRS may also have a period of maintenance care in the early months after their injury, while the health care team waits and watches to see if there is enough improvement to warrant more active rehabilitation.

Con's family want to take him home. He's still in PCU after many months in rehabilitation. Their two-storey house will need ramps, hoists, bathroom alterations, and a lift.

For the family, the first step is to take him down the street from the hospital in his wheelchair. Then in a maxi-taxi, maybe to a shopping centre for an hour or so. After a couple of months they will probably be ready to try a day at home with the help of attendant carers. Then overnight, and for a few nights—all the time the rehabilitation team helping the family to sort out any problems.

When he's home, he'll need two attendant carers all day and one at night for the rest of his life. This may be possible because Con's injury was a from car accident and he has compensation.

A person receiving maintenance care may be living:

- in a nursing home—although not all nursing homes can provide the therapies, care and environment needed by people in PCU or MRS. Many nursing homes cater mostly for older people, while people in PCU or MRS are often young;
- in a community house, where four or five people are cared for by staff who are on duty 24 hours a day. Arrangements need to be made for therapy and regular review by a doctor; and
- at home, cared for by family and other carers. This is a very large undertaking for any family, and families who choose to take it on will need a lot of support and help. You can expect the health care team to make sure these supports are in place. The home usually needs to be modified for a wheelchair, and for bathing. Families may provide some therapy (with training from the health care team), but outside carers are usually needed as well.

A trial period of care at home may give a family time to see whether home care is feasible in the longer term.

Some places that provide rehabilitation and/or long-term care may be able to provide 'shared care' with families—where, for example, the person goes home to the family for two or three days each week.

PALLIATIVE CARE

Palliative care is about the relief of pain and suffering for a person with a life-threatening illness. It is not just about care when people are dying.

Some people in PCU or MRS may seem to be in pain or discomfort, though it's hard to be sure, as responses are often very slow, and a grimace may be just reflex movement. If you are concerned, discuss palliative care with the health care team.

Palliative care doctors and nurses are experts in relieving pain and suffering, and they provide a range of other social, emotional and spiritual supports to the person and family. This care includes bereavement support to family and carers after a person has died.

WHAT IS THE ROLE OF FAMILIES, FRIENDS AND OTHER CARERS?

Families and close friends, where they are available, have a very valuable role to play in the care of people in PCU and MRS. You know the person and what he or she cared about, enjoyed and valued before the injury. Your voice is familiar, you can chat about family, friends, interests, play the right music and be a reassuring presence. If the person has any awareness of the world, family and friends are the people they may be most likely to respond to.

Attendant carers and volunteers can also assist people in PCU or MRS and their families.

> I provide a familiar voice and touch. I can read his signs of discomfort, I know which music he may recognise or what other forms of stimulation he may respond to.

ASSISTANCE FOR FAMILY AND CARERS

Few families can provide care alone. Ideally, families and friends will work with the health care team.

For this to be a productive partnership, you will need the team's active support. It would be helpful for you to keep a diary of care about your family member in MRS/PCU. This will assist in discussions with the health care team.

The health care team's support includes keeping you informed, involved and up to date with what is happening with the person. It may also include providing professional support for you to work through the many problems and difficulties that severe brain damage can lead to for families.

Caring for someone in PCU or MRS is enormously demanding. You will need some time off from caring, whether the person is in hospital or residential care, or at home. Access to respite care is important. It may be particularly difficult in rural and remote areas, but you can ask the health care team to help you with this.

Loss of income—your own or that of the person with brain injury—can often mean financial hardship for families.

For financial advice and assistance:

- Centrelink provides the carer's pension for eligible carers, and helps carers to contact agencies to find employment.
- Commonwealth Carelink Centres can provide information and services.
- Seek advice from the social worker in the hospital or rehabilitation facility, or from the case manager.

> I am a sole parent. Before Gail's injury my career supported the two of us quite adequately. With the impact on my emotional wellbeing, and her legitimate need for a familiar person alongside her through this ordeal, I have been unable to work for the past two years.

‘Centrelink expects me to leave my son and go back to paid work. The health system expects me to be available for meetings, equipment trials, appointments… Carers are squeezed, physically, emotionally and financially.’

THE MANY ROLES OF FAMILIES

Families caring for a person with a severe brain injury talk about the many roles they may take on. These may include the main hands-on carer, legal guardian and decision-maker, advocate, lay therapist and case manager, provider of practical support, stimulation and recreational activity, and financial manager.

This means a steep learning curve for most, and is very demanding. You are free to talk with the health care team about your roles and the decisions you have to make, and to seek their support.

RECOGNISING LIMITS

Depending on their resources, some families may choose to become very involved in the person’s day-to-day care, both in the short and longer term. You and your family may need help to cope.

Often it may be in the best interests of a person in PCU or MRS, or of the family, that care is provided in a setting other than home. Each person and family is different, and it’s important that family and health care team can openly discuss the care options.

BEING VALUED

Despite the challenges, many families speak of the strongly positive aspects of caring for a person with severe brain damage.

Whatever level of care you are able to provide, you can expect the staff in the hospital or nursing home to make you feel welcome and a valued part of the team.

PCU AND MRS IN CHILDREN

PCU or MRS in a child can be particularly difficult for families. It’s devastating, as a parent, to see your child so injured, to lose your hopes and dreams for your child. Parents may also feel a sense of responsibility and guilt.

Some want to care for their severely disabled child at home. Often there’s an expectation from the wider family, or the community, that you will do this. It can be an enormous burden, particularly when there are other children in the family, with their own needs and demands.

Georgie had a severe brain injury when she was five. Her parents say she’s a special person, but she relies on them for everything – feeding, toileting, showering, dressing – you name it, they do it for her. And they have been doing it for the last sixteen years. They are just not coping any more.

The family's thoughts and feelings are often complex and uncertain whilst trying to plan for their child's future care needs. It can be useful to share the many questions and concerns with the health care team so they can provide support and help.

IN RURAL AND REMOTE AREAS

The problems of profound brain damage are compounded for families and carers who live far from cities. There are few specialist services available in rural areas, and people in PCU or MRS are often cared for in city hospitals. Transport and accommodation may be expensive, and it may be difficult to visit regularly and keep up work commitments.

It may also be very difficult to take the person home, and to find therapy, support or suitable attendant carers or to find a suitable local nursing home or community house.

You can always discuss these issues with the social worker or other support staff to see what extra assistance may be available.

You can also ask the health care team to do things such as:

- planning meetings well ahead, at times to suit your schedules;
- using teleconferencing regularly to keep you up to date;
- being accessible to you by telephone or email and having a person on the health care team who is consistently available;
- mailing or emailing relevant information to you; and
- helping to organise local care and respite.

CARE AND CULTURE

Your cultural and religious background may have a strong influence on how you see illness, injury and disability, what care you and your family expect, and how you see your role in care. It is important to share with the health care team your culture and needs—the team would like to hear what is important to you, and how you would like your relative or friend cared for.

You have the right to an interpreter—ask for one if you are more comfortable in another language.

BEING VULNERABLE

People in PCU or MRS are particularly vulnerable members of our community. Because they are unable to communicate, they can be at risk of abuse, neglect or exploitation from people in positions of trust. Abuse does sometimes occur. It could be financial, physical, emotional or sexual, and may come from paid carer, family, or other.

People in PCU or MRS have a right to protection and care. Any suspicions of mistreatment should be reported immediately. If the person is in an institution, in the first instance concerns should be raised with management. If the person is being cared for at home, various government agencies can help, including the police, the department for community services in your State or Territory, or the Office of the Public Advocate or Guardian (depending on the nature of the suspected mistreatment). See page 18 for contact details.

3 KEEPING COMMUNICATION CHANNELS OPEN

The best care for people in PCU and MRS, and the best decisions about that care, happen when everyone works together as a team—the family, doctors, nurses, therapists and other carers.

Teamwork depends on open, two-way communication between all members of the team, including families and carers. The treating team should be available to meet regularly with you and your family.

> I have, continually, to find the strength and assertiveness to create my own opportunities for communication regarding his care.

WHO MAY BE INVOLVED?

Usually this teamwork and communication will include close family and all those involved in the person's care. Sometimes there is disagreement within families about whom the doctors should talk to. If this can't be resolved, the person's 'representative' is the one to decide—this is discussed on page 18, 'Who has final responsibility for decisions?'.

The health care team must seek the representative's consent before providing any information to people who are outside the health care team—for example, lawyers, insurers and case workers and sometimes even past or current family members. In giving consent, it must be with the person's best interests in mind. This includes reflecting his or her wishes ('best interests' are discussed on page 19).

TALKING WITH THE HEALTH CARE TEAM

You can expect the doctors and others on the health care team to be honest and open with you about the person's condition, what care and treatment he or she needs, and what the prospects are for improvement. This should be in words you can understand—not medical jargon. If you don't understand something, ask for an explanation.

Particularly in the early stages, it's very difficult to take in and remember everything you are told. This is quite normal. Talk often to the health care team, ask what you want to know, when you want to know it. Don't worry if you need to ask the same thing a number of times. There will be time to talk things over.

Equally, the health care team wants to listen to and learn from family and friends. You know what the person was like before the brain injury, his or her likes and dislikes, habits, skills and interests.

> As my daughter's legal guardian, I see my role as the decision-maker and I need her medical team to provide me with accurate information and opportunities for open discussion on options and alternatives. I need these discussions to take place in privacy, not a hospital corridor!'

I am determined to walk alongside my son on this journey. I see that as my responsibility but also a privilege. There are so many things that can make a difference to the quality of his day. What could be more important?'

The team also expects to listen to the family's questions, needs, opinions and observations of the person since the brain injury. You should feel free to discuss your hopes for the person and any doubts, concerns, and difficulties you are having.

Often, one of the most difficult things for families is the uncertainty. Will the person improve? How much? Or will they always remain as they are now? The doctors can give some guidance, but the answers to these questions will remain uncertain. Only over time will the picture become clearer.

FORMAL MEETINGS WITH THE HEALTH CARE TEAM

On occasion, the doctors will organise a formal meeting between family and health care team to discuss and make decisions about the person's condition and future care. Families can also request such meetings.

You can expect the health care team to bring to the meeting a clear and up-to-date understanding of where the person in PCU or MRS is up to, what his or her prospects are, what the uncertainties are, and what treatment and care options are available.

COME PREPARED

It often helps to have someone with you—two people will remember what's said better than one. You might ask the team if they mind if you tape record the discussion, so you can play it back later. Prepare your questions beforehand, write them down so you won't forget them, and take notes if you wish to. Ask questions of the team, and offer them your own viewpoint. Ask the team for written information as well. If you are keeping a care diary, it can help to bring this to the meeting.

There should be an agreed brief written record of the meeting so that what has been discussed is formally acknowledged, and noting issues for follow-up or action.

UNDERSTANDING THE TREATMENT OPTIONS

If there are decisions to be made, families need to understand clearly what the options are, and the pros and cons of each option. Always feel free to ask questions and voice any concerns or doubts you may have. There are no right or wrong questions.

When looking at different treatment options, it's important to know whether a treatment does what it's intended to do, how well it works, and what the disadvantages are. However, because PCU and MRS are rare, it may be difficult to find definite answers on how well treatments work.

COMPLAINTS

Each State and Territory has an independent health complaints service. If you have concerns about the treatment and care of your family member or friend in MRS or PCU you can contact the office of your local health complaints commissioner:

New South Wales

Ph 1800 043 159 (toll free in NSW) or (02) 9219 7444
Email hccc@hccc.nsw.gov.au

Victoria

Ph 1800 136 066 (toll free in Victoria) or (03) 8601 5200
Email hsc@dhs.vic.gov.au

Queensland

Ph 1800 077 308 (toll free in Queensland) or (07) 3120 5999
Email info@hqcc.qld.gov.au

South Australia

Ph 1800 232 007 (toll free in SA) or (08) 8226 8666

Western Australia

Ph 1800 813 583 (toll free in WA) or (08) 9323 0600

Tasmania

Ph 1300 766 725
Email health.complaints@justice.tas.gov.au

Northern Territory

Darwin Ph (08) 8999 1969
Alice Springs Ph (08) 8951 5818

Australian Capital Territory

Ph (02) 6205 2222
Email human.rights@act.gov.au

4 MAKING DECISIONS ABOUT CARE

There are always new decisions to be made about care and treatment for a person in PCU or MRS. Some common questions are:

- What is in the person's best interests?
- How intensive should treatment be?
- Should a treatment be started or continued?
- Where should the person be cared for?
- Do some treatments impose an unreasonable burden?
- What is it realistic to hope for?

Decisions about care are often limited by the resources available at the time.

It may help to think in terms of levels of care: acute care, rehabilitation care and maintenance care. After a time in acute care, the person may begin a trial of rehabilitation therapy. Later, when rehabilitation therapy is scaled down, maintenance care will be provided while continuing to watch for any signs of change. Palliative care may be required if the person is experiencing distressing symptoms or is nearing the end of life.

The person is always to be cared for, even though levels of treatment may change. Making decisions about care is a matter of reviewing and deciding what is appropriate to the person's needs at the time.

WORKING TOGETHER TO MAKE DECISIONS

Everyone has the right to agree to or refuse medical treatment, but people in PCU or MRS cannot exercise this right. Others must make decisions for them[1].

Usually, decisions are made by the family or other carers and the health care team working together and discussing all of the available options.

The doctors will advise on what they think is the best course of action—what treatment they believe is appropriate and available for the person. This advice will be informed by their specialist knowledge and their experience.

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[1] Unless the person has prepared a legal and binding advance care directive (see page 21).

WHO HAS FINAL RESPONSIBILITY FOR DECISIONS?

Very rarely it is difficult to reach agreement. Legally, there is usually one person who has the authority to speak on behalf of someone who can't make his or her own decisions.

This person, called the 'representative[2], may:

- have been appointed by the person when he or she was well;
- be recognised legally because of his or her relationship to the person – for example, spouse, carer or next of kin; or
- be appointed by a court or tribunal.

If someone is concerned that a representative is not acting in the person's best interests, then he or she should seek to have the appointment legally reviewed.

Sources of advice on the appointment of a representative are:

New South Wales

Office of the Public Guardian, free call 1800 451 510

Victoria

Office of the Public Advocate, free call 1300 309 337

Queensland

Office of the Adult Guardian, free call 1300 653 187

South Australia

Office of the Public Advocate, free call 1800 066 969

Western Australia

Office of the Public Advocate, free call 1300 858 455

Tasmania

Office of the Public Guardian, ph (03) 6233 7608

Australian Capital Territory

Office of the Public Advocate, ph (02) 6207 0707

Northern Territory

Office of Adult Guardianship, ph (08) 8922 7343

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[2] Sometimes the terms 'substitute decision-maker' or 'agent' are used.

BEST INTERESTS

Decisions about care must always be made in the best interests of the person in PCU or MRS. A number of things must be taken into account.

First, what would the person himself or herself have wanted?

Decisions need to respect the person's own beliefs and values and the things he or she holds to be most important, even if these differ from the family's views.

Decisions also need to respect the person's wishes about treatment, if they are known. This is not always straightforward. It's easier to be sure if the person has written them down somewhere, or if you or other members of the family can recall particular situations where the person said, for example, 'I wouldn't want that for myself'. (See also the discussion on 'Advance care planning', page 21.)

It's also important to know whether the person was making a well-informed, considered decision. What was their state of mind at the time, and were they thinking of a state such as PCU or MRS, or a quite different scenario? Even if previously expressed wishes do not apply directly, they are useful in understanding a person's values and beliefs.

What an active healthy person may see as an unacceptable level of disability may, in fact, be acceptable when a person is actually in that situation.

What the family thinks is also relevant, but only if it is clear that this is in line with what the person would have wanted.

Second, what does the health care team (the doctors and others) believe would benefit the person, given the resources available?

The pros and cons of any treatment need to be weighed up. What benefits does it offer? What risks or burdens might it impose? What would happen if it's not carried out—would the person be worse off, or possibly better off? What other treatments are available, and what are their pros and cons?

Once again, the answers to these questions are often unclear.

Any treatment must have a clear purpose, with clear and realistic goals, so it is possible to assess whether these goals are achieved. It's the clinicians' job to make sure of this.

> I want my son to live at home with me eventually. I want him to hear familiar voices and familiar music, smell his favourite foods cooking. I want to be able to wheel him outside so I can chat to him while I'm doing the garden. I want to be available to him without having to spend my life in a nursing home. I want him to live in the community in his more normal and familiar environment. I expect to receive adequate funding so that he can have attendant carers at home and I can return to work, at least part time. Why should two lives be destroyed for the sake of some funding for attendant care? I'm sure it's cheaper than building institutions.

DIFFERENT POINTS OF VIEW

Sometimes the doctors and the family may have different views of the person's best interests. Doctors might suggest a treatment that the family feel the person would not have wanted. Or the family or representative may want a treatment that the doctors believe is not appropriate.

Generally such things are readily resolved in the context of a good relationship and communication between the health care team and family.

Making decisions about risk can be difficult, and often there is no one right answer. For example, should a person in PCU or MRS be given some food or drink he or she used to enjoy (eg, tea, ice-cream), even though the health care team knows it might 'go down the wrong way', into the lungs? One consideration here might be the family's knowledge of the sort of risks the person would or would not have been prepared to take.

AVOIDING OR RESOLVING CONFLICT

Families, carers and health professionals generally want to do all possible to give a person in PCU and MRS the best care, even if they don't always agree on the best way to achieve this.

Where there's open, two-way communication between family and health care team, different viewpoints can usually be reconciled.

There are various practical ways to prevent argument or resolve different points of view:

- Maintain regular communication with the health professionals.
- If the person is in hospital, speak to the hospital's patient advocate.
- Seek a second opinion.
- Seek review at the tribunal[3].

Differences of opinion can also occur within families, but discussing issues openly as they arise can help to avoid real conflict.

Mediation is an option if conflict cannot be resolved. There are usually patient liaison officers in hospitals, and many community organisations offer mediation services.

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[3] For advice on this, contact those listed on page 18.

SECOND OPINIONS

You always have the right to ask for a second opinion on your family member in PCU or MRS. Some families find this very helpful, to confirm that what's being done is the best possible, or to resolve any doubts they may have.

If you want a second opinion, the hospital or health care team can provide you with some options. You may accept these suggestions, or choose another person—but it's important that the person you choose is suitably qualified.

A second opinion may be covered by Medicare, but there may be some fee above this.

ADVANCE CARE PLANNING

Some people quite deliberately think in advance about what they would want done if they become unable to make their own decisions about health care. This 'advance care planning' may simply involve discussion with family, friends, health professionals or other carers; or the person may formally appoint someone to be their representative should he or she lose the capacity to make decisions.

A person's wishes may be recorded in several ways:

- The person's doctor may keep notes of what has been said in discussion between the two.
- The person may write down some general principles about what he or she would like done in the future, or may be more specific about treatments he or she does or doesn't want.
- The person may make a formal 'advance care directive'—a set of instructions for future health care. This may be legally binding in some Australian States and Territories.

Sometimes, new information may lead the doctors to question whether the person would still make the same decision, or the doctors may feel that the advance care directive now goes against the person's best interests. This can be decided by a court or a tribunal, which will consider whether the person was adequately informed, competent, and acting freely. Family, carers and anyone involved in the person's care can request review by a tribunal (see page 18 for contact details).

SHOULD TREATMENT EVER BE WITHDRAWN?

The longer a person remains in PCU or MRS without any sign of change or improvement, the less likely it is that there will ever be any significant recovery.

Sometimes the person may develop a new illness or one that is a complication of the PCU or MRS or its treatment. For example, feeding by nasogastric tube might lead to repeated chest infections; or with ‘PEG’ feeding (a tube directly through the skin into the stomach), the surrounding skin may become ulcerated.

After perhaps months or years, the question may be raised whether or not to continue a particular treatment. Again, the central—and only—concern is the person’s best interests.

Decisions to withdraw a treatment or change a care plan are often very difficult to make. Families and the health care team need to discuss them carefully together, always taking into account any wishes the person may have expressed before the brain injury.

As part of the health care team’s care for the person in PCU or MRS, you can expect the team to provide the family with advice and recommendations on the benefits or limitations of continuing treatment and therapy. In general, the aim is not to place the burden on the family to decide, but to work together to make the best decisions.

The question is never whether the person’s life is worthwhile, but whether a treatment is worthwhile.

The concepts of ‘burdensome’ and ‘futile’ treatment may be helpful in making these decisions.

‘BURDENSOME’ AND ‘FUTILE’ TREATMENT

Treatment can bring various benefits. It may slow down a disease, help to sustain life, reduce disability and improve health, or relieve distress or discomfort.

A treatment that achieves none of these benefits for the person is described as ‘futile’. A futile treatment should not be started or, if it has been started, should not be continued.

A treatment that has some benefit may, nonetheless, be ‘burdensome’ in a variety of ways, chiefly when it causes distress, suffering or other difficulties to the person. Sometimes these burdens may outweigh the likely benefits for the person. A decision

After a year in the rehabilitation hospital after a catastrophic accident, Bill showed no improvement of any kind. He reacted to no-one and nothing, and his feeding tube was causing problems. His family decided, together, that he’d not have wanted the level of treatment he was receiving to be continued. The hospital supported them in their decision. A palliative care physician took over Bill’s management, and he was moved to a room where the family could be with him day and night in privacy. The artificial feeding was stopped, but his mouth was kept moist and medications to control symptoms were continued. He died four days later, among family and staff.

might need to be made to change the level or nature of treatment if it is felt to be overly burdensome.

When these decisions are made, the family and health care team will take into account:

- the person's and family's circumstances, experience of illness; and culture, beliefs and preferences; and
- the burden or cost of the treatment, and the resources available to the family and community.

The decision is one to change the treatment being provided, not to withdraw care. Care should always continue, including treatment that is of benefit to the person and is not overly burdensome.

Decisions on whether a treatment is of benefit, or is overly burdensome, are made in the light of:

- the doctors' opinion about the effects of the treatment;
- what was important to the person in PCU or MRS; and
- the various burdens the treatment involves.

RESUSCITATION

You can expect that the issue of resuscitation will be raised with you, as it is raised in a range of health care settings.

It is usually helpful for doctors, other professionals, families and carers to discuss together what would be done if a person in PCU or MRS stops breathing or the heart stops pumping. Should resuscitation be attempted? Those caring for the person at the time need to know what is required if there is an emergency.

Decisions about resuscitation are decisions about whether the procedures involved are burdensome or futile. They are best made in the light of a medical opinion about the benefits and risks of resuscitation, and with knowledge of what was important to the person in PCU or MRS. Decisions are made in the person's best interests, taking into account any previously expressed wishes or directives.

The decision may depend in part on what causes any crisis. For example, if a mishap such as choking causes the person to stop breathing, then it is easily treated. This is very different from a cardiac arrest caused by a serious progressive condition where there is little chance of recovery.

The decisions are documented by the doctor as instructions to follow if the person stops breathing or the heart stops pumping. You can ask for a copy of these instructions.

5 CARING FOR FAMILIES AND CARERS

IS IT NORMAL TO FEEL LIKE THIS?

Throughout this journey with your family member in PCU or MRS, you may experience many different thoughts and feelings. First, there is the shock of the initial injury and the often life-threatening time in acute hospital care; then coming to terms with how things are now, the loss and change, and the decisions to be made about care.

Feelings are often confused and tangled—great sadness, anger, pity, blame, hope, denial, guilt, depression, love, anxiety, panic, frustration, helplessness, hopelessness. The feelings may come intensely, and in waves, often without warning. There can also be some very positive aspects to caring, arising from a sense of involvement, commitment, loving and giving.

We all respond differently. There is no right or wrong way to react, and there are no right or wrong thoughts or feelings.

ASK FOR HELP

It is expected that families will seek and receive support as needed, both at present and into the future.

Ask for and accept help when you need it. There may also be a need to plan for a time when you are unable to continue care.

You may have your own supports, for example from friends, community and spiritual advisors. Your general practitioner and/or the health care team should be able to link you with professional counselling when this is needed, to help sustain you in your demanding role. They should also be able to link you with sources of practical help. Your local Carers' group may also be of assistance.

Make sure that you and your family continue to look after yourselves. Carers often neglect themselves and the life they previously enjoyed—make sure you find ways to stay healthy, both physically and mentally. Take regular breaks from the demands of supporting the person in PCU or MRS. Find someone you can share your feelings with. Look after yourself, don't make unrealistic demands on yourself, and keep up some social contacts.

WHEN A PERSON IN PCU OR MRS DIES

When a person who has been in PCU dies, families and carers may feel very ambivalent and uncertain about how to react, especially if treatment was discontinued or withdrawn. Grief may be mingled with relief, perplexity, exhaustion and guilt.

Many families gain strong support at this particularly difficult time through family, friends, skilled professionals, and their spiritual advisor.

The health care team may have offered valuable support while your family member was in their care. It sometimes helps to make contact again, to ask them any questions you may have about the person's care and death, or simply to 'sign off' and say your goodbyes after what may have been a long and difficult journey of care.

SOURCES OF HELP AND INFORMATION

The health care team, including social workers, and the chaplains or spiritual advisers involved in the care of the person in PCU or MRS can be sources of help and information for families and carers.

A number of other organisations may be able to help. What organisations can offer may change over time, so if what you need is not available from one, try another.

Potential sources include:

Brain Injury Australia (BIA), ph (03) 9497 8074 or email admin@bia.net.au. For information see BIA's website www.bia.net.au

BrainLink Services Limited, free call 1800 677 579 or email admin@brainlink.org.au. For information see BrainLink's website www.brainlink.org.au

Carers Australia, ph 1800 242 636 or emal caa@carersaustralia.com.au. For information visit the website www.carersaustralia.com.au

Lifeline, free call 131 114, a 24-hour telephone counselling service

Telephone Interpreting Service, free call 131 450, available for calls to the above centres—call and ask to arrange an interpreter.

Making Decisions About Tests and Treatments: principles for better communication between healthcare consumers and healthcare professionals, published by NHMRC (2006), available from www.nhmrc.gov.au, or free call 1300 06 4672.

6 GLOSSARY

ABI	Acquired brain injury
advance care directive	A set of instructions for a person's future health care to be carried out in the event that he or she is unable to make decisions. It is intended to be binding. In some jurisdictions advance care directives have a legal status requiring compliance by caregivers.
advance care planning	The processes by which a person seeks to provide advance guidance or instructions about how health care decisions are to be made for him or her, if and when he or she becomes unable to make decisions.
best interests	Assessment of a person's best interests in relation to a treatment decision must take into account • the person's values, beliefs and critical interests; • the person's previously expressed wishes, to the extent that they can be ascertained, and whether the present circumstances correspond to the situation that the person imagined when expressing or recording those wishes; • the wishes of a nearest relative or other family members, if it can be confidently assumed that the family's wishes are aligned with the person's interests; • the benefits and burdens of treatments, and the consequences to the person if the treatment is not carried out, having regard to the level of confidence about prognosis at the time a decision is made; • the relative merits of any other treatment options; and • the nature and degree of the risks associated with treatment and/or with those options.
brain death	A state in which all function of the brain has permanently ceased—that is, the person has died. Breathing is maintained artificially by a mechanical ventilator, the heart keeps beating autonomously for a time, and other organs may continue to function for a time. Brain death is diagnosed by assessing that the underlying cause and the extent of brain injury is such that all brain function has ceased and (after excluding factors that might temporarily suppress brain function) that this cessation is permanent. Over a period of time, the clinicians caring for the patient carefully observe the development and progress of the injury or disease. If it is thought that all brain function has been completely and permanently lost, doctors perform a series of clinical tests to confirm that the loss of function involves the whole brain, including the brain stem (which is involved in vital reflexes, eg, coughing, gagging, breathing). If clinical testing is not possible, then brain death is confirmed by special scans to establish absence of blood flow to the whole brain.

care	Attending to the person's needs and including therapy.
care diary	A diary used by members of the family and carers, to record their observations and plans, and to inform discussion with the health care team.
carer	Any person who provides care to a person in PCU or MRS, whether paid or unpaid.
clinician	Any health professional directly involved in a person's care, involving medical, nursing and allied health staff.
coma	A state of presumed profound unconsciousness from which the person cannot be roused when examined. Coma is not brain death; some brain function remains, and some or all may be recoverable.
consent	The act of assenting to a proposed course of action or inaction. In medicine it is usually the case that—unless it is an emergency—consent must be adequately informed.
critical interests	Those matters of conviction or opinion, whether articulated or not, that are particularly important in an individual's life.
cultural and linguistic diversity (CALD)	Refers to the wide range of cultural groups that make up the Australian population and Australian communities. The term acknowledges that groups and individuals differ according to religion and spirituality, racial background and ethnicity as well as language. The term CALD background reflects intergenerational and contextual issues, not just migrant experience.[4]
death	The final cessation of the integrated functioning of the body. Integrated functioning is a characteristic of living beings. Death is observed to have occurred when there is irreversible loss of brain function or irreversible cessation of circulation.
dignity	A complex notion combining respect for the worth of the individual as a member of the human family. It is thus an attribute of the kind of being who can normally make autonomous, rational choices, and it involves respect for that person's autonomy. Dignity thus incorporates respect for a person (inviolability), respect for his or her rational choices (autonomy), and respect for his or her privacy. An individual who has diminished capacity to make rational choices retains dignity through membership of the human family.

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[4] *Cultural Competency in Health: A guide for policy, partnerships and participation*, NHMRC 2005

duty of care	An obligation to be careful in the actions that a person takes. The duty is owed to all those whom the person should reasonably foresee will be affected by his or her actions. Broadly speaking, it is the moral or legal obligation that one person owes to another, either simply because the other is a fellow human being or because the person stands in a particular relationship to the other that gives rise to specific obligations.
duty of disclosure	The ethical obligation to disclose information about medical treatment that requires meeting an objective test (where the patient is informed of the usual risks associated with the treatment), and a subjective test (where the patient is provided with the particular information he or she has sought about the treatment).
family	Those closest to the person in knowledge, care and affection. This includes the immediate biological family; the family of acquisition (related by marriage/contract); and the family of choice and friends (not related biologically or by marriage/contract).
formal meeting	A pre-planned, structured meeting between health care team and family, to discuss care, goals and progress.
futile treatment	Treatment is futile only if it produces no benefit to the patient (ie, does not slow down the progress of disease, sustain the patient's life, reduce disability and improve health, or relieve the patient's distress or discomfort). Treatment ought not to be continued or initiated if it is futile.
health professional	All of those in the health disciplines who may provide information and advice, but are not necessarily in a relationship of clinical care with the person in PCU or MRS.
ICU	Intensive Care Unit
justice	Justice as a virtue is the recognition of the needs of others and the inclination to respect their needs based on common humanity. As a normative principle it means ensuring that there is fair distribution of the benefits of or access to goods and services, equality of opportunity and access, no unfair burden on any members of the community or on particular groups, and no exploitation or discrimination.
mediation	The involvement of an independent person to hear the differing views and aid resolution.
minimally responsive state (MRS)	A state that may arise when a person has emerged from coma or PCU. There is a minimal level of purposeful response, with discernible but inconsistent evidence of consciousness. Cognitively mediated behaviour occurs often enough or for long enough to distinguish it from reflex behaviour.

NHMRC	National Health and Medical Research Council
nursing home	A form of residential care for people who are highly dependent.
post-coma unresponsiveness (PCU)	A state or condition in which a person has emerged from coma to the extent that he or she has sleep/wake cycles, but there are no observable purposeful responses to stimuli.
quality of life	A term used with respect to assessing the outcomes of interventions. It may be used in a formal way engaging methods of scoring patient disability, discomfort and preferences.
representative	A person's representative is responsible for making decisions in the best interests of that person, when the person becomes unable to make his or her own decisions competently. The representative must be adequately informed about the person's circumstances and treatment options, as well as about his or her values, beliefs and previous wishes. The representative may be appointed previously by the person; appointed by a court or tribunal after the person became incapable; or have legal authority automatically, as the person's spouse, carer, other next of kin or other person specified in the applicable legislation.
residential care	A nursing home or hostel.
respect	Respect for human beings is recognition of each individual's intrinsic worth or value as a person. This is often referred to as their inherent human dignity. Respect requires having due regard for welfare, beliefs, perceptions, customs and cultural heritage, both individual and collective. It involves protecting the privacy, confidentiality and cultural sensitivities of individuals and communities (see Dignity, above).
right to refuse treatment	The right to refuse treatment is implied by the moral and legal obligation to obtain consent. In some jurisdictions it is also explicit in statute. However, it is also a right that may continue to be exercised after a person has previously consented, for example, that treatment be discontinued.
rights	For the purposes of this document, 'rights' refers to moral rights, and not legal rights. A moral right is an entitlement or justifiable claim. It is often expressed as a relation between the right-holder and that to which he or she is entitled, such as a person's right to health care or housing or freedom of speech. However, the expression of a right also implies that there is a person or institution in duty bound to respect or grant that to which the right-holder is entitled.

second opinion	A professional opinion given independently of those caring for the person.
therapy	A treatment that aims to improve function, limit deterioration, or relieve distressing symptoms.
tribunal	A legal authority with a statutory power to make decisions about representation and care.
vegetative state (VS)	A term, sometimes qualified further by the terms 'persistent' or 'permanent', which is also used to describe the condition of post-coma unresponsiveness.