

A CALL TO CONSCIOUSNESS

The ComaCARE Journey
2005–2009



Communication
COMAadvocacy
Research
Education

HEARING THE SILENT VOICES

OUR BELIEF

We believe that coma is a condition where persons are unable to respond adequately to their inner states and their environment. We also believe that communication is possible during this extreme altered state of consciousness. This is a belief that bridges medical, social, cultural and religious understandings. We believe that patients and care givers stand to benefit by exploring and incorporating common approaches in the care of coma.

OUR VISION

Coma patients are given the maximum opportunity to live as fully as possible and participate in making decisions about their own care and status.

OUR MISSION

CARE service development, coma communication training and counselling.

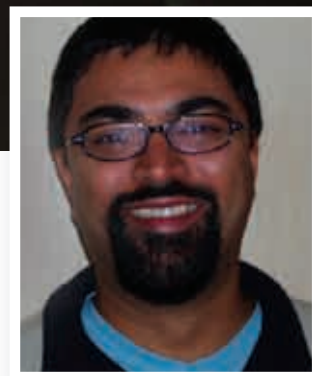
ADVOCACY – protecting and improving a coma survivor’s health, social and economic rights and status.

RESEARCH of best coma practice – local and international.

EDUCATE professionals and the public in order to create a supportive environment for coma patients and their families.



All of us involved in the care of coma patients
need to shift OUR consciousness.
Only then will be be able to realise our dreams



CHAIRPERSON'S REPORT

It is with great excitement, a deep sense of hope and sincere gratitude that we in ComaCARE conclude our fourth year.

All our new projects make us feel very excited, while we hope to meet the needs of more and more patients and families. We sincerely thank all our volunteers, the family members and friends of coma patients, as well as our Board members and Executive Director, Jan Webster, for all their efforts. Many people have volunteered and done so much – the organisation has grown with the support and love of our colleagues and friends.

We are particularly grateful for the patience and guidance of staff at Groote Schuur Hospital (GSH) who have embraced our learning curve with generosity and open minds. The Norwegian Centre for Human Rights (NCHR), which funds human rights programmes that focus on research and advocacy for people with 'silent voices', gave us a grant which enabled us to progress even further.

The Nussbaum Foundation joined us in training staff and volunteers to care more consciously for coma patients. The D.G. Murray Trust has supported our nurse training development. We also thank individual and corporate donors who have given funding to pay for the transport costs of volunteers who sometimes travel up to 30 kms to the bedsides of coma patients. We are therefore deeply appreciative of our donors for their support.

People working in ComaCARE realise that supporting patients in a coma is 'pioneer' work. When a loved one goes into a coma, families often feel frightened and helpless because they feel as though they have 'lost' their loved one. Even though we know the person is still with us, we need to step beyond our own fears to reach them and be with them.

We're excited about the future, because as caregivers we are learning all the time while we help patients with their level of consciousness. We constantly have to change our understanding to meet the needs of patients, families and caregivers around the bedside.

We dream of many things for the future: having 'specialist' trained coma workers in hospitals, hospices and in home-based care teams; a coma care counselling room in every big public and private hospital; a more informed and educated public; a coma and consciousness think-tank; and finally we would like to produce a book which reflects the voices of coma survivors and a film about the challenges faced by coma patients.

All of us involved in the care of coma patients need to shift our consciousness. Only then will be be able to realise our dreams. We need to work together to help the 'silent voices' of coma patients to become clearer and louder.

A handwritten signature in blue ink, appearing to read 'Reno Morar'.

Dr Reno Morar
Chairperson

**Do not knock on a door more than twice.
A closed door is not a rejection – just an
indication of poor timing!**



THE DIRECTOR'S REPORT

In this year we have reached a point in our journey of creating consciousness about (un)consciousness that we know each step brings us insights. In this report we ask you to share those moments of awakening and awareness which deepen our experience.

Coma is a hidden blight in Africa. High levels of trauma due to road vehicle accidents and violence, strokes, diabetes and metabolic changes at end stages of life such as in AIDS and cancer mean that many families face a coma experience. Unfortunately coma patients in trauma wards are mainly young men from disadvantaged backgrounds and their families carry the triple burden of economic, social and emotional difficulties.

When the founders of ComaCARE met in July 2005 it demanded a leap of faith to begin with no roadmap. We had knowledge of extreme altered states of consciousness from many viewpoints: medical, psychological, social and spiritual and many of us had been touched personally by a coma experience.

Our first few months were spent listening to coma survivors and their families and ensuring we were not replicating an existing service. On the contrary, the need was clear for an organisation which provided bedside care and counselling for patients, their families and care givers, advocacy for the rights of coma patients, research into the best coma care practice and a need to educate the public about coma. This integrated approach developed our name ComaCARE and our slogan, "Hearing the Silent Voices".

Like so many new initiatives, the birth of ComaCARE is material of myth – we started working in a garage with no money, staff, equipment nor access to coma patients.

From our inception we chose to develop a community/public partnership to add value to the care already provided by the state for the majority population in South Africa.

Within six months trained coma volunteers entered the neurosurgery ward of Grootte Schuur Hospital to add value to the existing care programme.



Our approach is that we stand for the rights and care of all parties in and around the bed and know that the patient, his family and care givers are all tested to the extreme in an intensive care and high care neurosurgical scenario.

In the years that have followed we have renovated a neurosurgery ward, developed an innovative bedside communication and care programme, a multileveled training programme for volunteers and staff, conducted and supervised research and advocated for rights and better service provision for coma patients, their families and care givers. None of this would have been possible if it were not for the open-mindedness and encouragement of the hospital leadership and care staff and our volunteers.

THE DIRECTOR'S REPORT

This model of community involvement in a high care environment is still relatively new, but already indications are that components of it can be replicated in similar environments.

So many people ask us, "What do you actually do at the bedside? Surely a coma patient cannot hear you?" In the article, "The ComaCARE Approach" which follows, I hope you will understand the depth of this work, the care required to conduct it and the learning process we are all undertaking.

I am so grateful to all volunteers and staff members who have supported ComaCARE. It is these men and women who have imbued us with spirit. I would also like to thank the Chair and Executive of the

ComaCARE Board and past and present members who served us so diligently. As our Chairperson is oft heard to comment, "ComaCARE business unusual".

I continue to be amazed by the openness and kindness of the staff of Grootte Schuur Hospital and wish to thank them for all the care that they offer in a world of relentless trauma and the patience they have shown a community based initiative struggling to find a relevant role.



Jan Webster

Director



The ComaCARE staff team has grown in response to our awareness of the needs of patients and families. Back row: Olga, Rose, Thelma, Paul, Nonkululeko, Di, Jan, Thandiwe. Front Row: Nicia, Elizabeth, Noluvuyo, Nosipho, Precious. Absent: Cynthia, Azeza.

Listening is the root of relationship,
talking is merely the twig

THE COMACARE APPROACH

I would like to begin this section by thanking my coma teachers. Who they are may surprise you – as many of them are not highly educated, most are unemployed and engage in high risk behaviours. Hardly teacher material one would think. Yet these young men have travelled further than many of us, because they have ventured into an altered state of consciousness to deal with their pain and trauma.

We have all experienced an altered state of consciousness to some degree – at one end there are day dreams, night dreams, prayers, meditation and trances and further along this consciousness continuum are psychiatric conditions, Alzheimers, delirium and the extreme altered state of consciousness known as coma. You will note that as we move along this continuum of consciousness there is less understanding and tolerance by society for these states.

So, propelled into this “strange state” involuntarily, many of my teachers want to forget the experience as soon as they are able, while others want to explain what it was like “in/out there”. At ComaCARE we believe that these patients have a lot to teach us about their experience and what their care needs were during that time.

This stance can be controversial in that some neuroscientists would say that the brain is the creator of consciousness and when stimulated or damaged certain parts of the brain can create out of body experiences, delirium and hallucinations which we would be quite mad to take seriously.

However, if we follow this logic then the “normal stimulated” brain also creates the emotional experiences which leave us happy, depressed and

angry and therefore none of our subjective, everyday emotions should be taken seriously either.

At ComaCARE we have chosen to work with the subjective experience of the patient, although it may not be a reality we perceive or can share. We also believe that coma patients, far from being unconscious and unaware may be hyper-conscious and hyper-aware of those around them. In the words of our Board member, John Cullom, coma survivor (now deceased), *“I was aware of those around my bed preferring it when I felt feelings of love and kindness and care rather than anger, sadness or fear.”*

To accompany coma patients in their altered state of consciousness, we are very sensitive to:

Atmosphere around the bed, ensuring it is a gentle space.

Breathing with the patient to match their rhythms
Introducing ourselves each time in case memory has been impacted by injury.

Touching the wrist and speaking in short sentences to avoid secondary trauma.

Observing any changes in breathing, movement, sounds.

Feedback to the patient any signs we can see/feel or hear.

Copy any signs the patient makes to reinforce the communication.

Amplify the signs by asking them to be repeated or enlarged so that they can turn into signals.

Resist a little to see if the patient pushes back – juice in the tank!!

Enable expression any way the patient can manage.

THE COMACARE APPROACH

This little technique demands patience, presence and respect for the efforts of the patient. It is not arousing or waking them up – but following their own processes.

At ComaCARE, we believe the brain is working hard to heal itself and over-stimulation can also be harmful. Our volunteers and Patient Advocates sit at the bedside awaiting a sign from a coma patient. The patient is not talked at, but listened to.

In recovery, patients will sometimes tell us amazing stories of their journeys while they were in coma. We use therapeutic techniques to ascertain whether the experience has meaning in the person's daily life.

One man was on a ship, but it wouldn't sail. The Captain of his ship was Jesus, but he couldn't sail the ship because the sails were knotted. We helped him explore this experience until he could appreciate where in his daily life he was unable to sail his own ship.

In addition to bedside care, we also work with the family. Coma patients are not neutral and have occupied a position within the family. Families are sometimes angry at the patient and we counsel them to remember who he was as a young man, his hopes and dreams and in this way unfreeze the position he occupied at the time of the trauma. Families also need care and attention, information and sensitivity through this difficult time.

Not all the patients we work with recover. A large aspect of our work is to be with the dying and their grieving families. In hospitals, the body is removed as quickly as possible and no rituals or blessings take place unless individual nurses are moved to do so. Nurses speak of stress of this unacknowledged part of their lives.

We now use a memory card to acknowledge the

patient who has died, their families and those who cared for them and offer a counselling space for care staff.

Are patients unaware? Reading Christine's story below, we are all humbled by how little we know about consciousness. We remain learners; appreciating and listening to the patient's experience.



I had been sitting with Merle for about 30 minutes in silent, open awareness, simply being present to our moment-to-moment togetherness, when two nurse aids arrived to change and turn her. During their interaction with Merle, I felt tension and resentment build up in me as I witnessed their struggle to tend to her exceedingly heavy body. They repeatedly asked her to assist them, but Merle kept her eyes closed, her head averted. After the nurse aids left I sat back down by Merle's bedside, but I could feel the contraction of my judgements turn into tension in my being. I didn't really want to be there anymore. My breathing was shallow, my mind cluttered with stray thoughts. It was then that Merle suddenly turned her head to me, looked me straight in the eyes and said, "Could the person who was here earlier please come back?"

Christine Nachmann

When my heart opens to patients,
my hearing improves



The ComaCARE volunteer team

THE CARE PROGRAMME

The coma patient

In the neurosurgery wards of Groote Schuur Hospital, coma patients are mainly young men who have been involved in motor vehicle accidents or violence.

Annually the staff care for 1000 patients and approximately 50% of them move through the coma state. When the patients leave the intensive care unit, they are moved to a high care ward and if they survive will eventually be sent to a step down facility or home. When a patient is brain injured, he/she may be left with a personality disorder, physical affliction or mental challenges. Their families need care and attention at the acute and long term stages of recovery.

Neurosurgery nursing is very challenging. The patient requires special attention – a brain injured patient cannot explain if he/she is uncomfortable or worried or frightened. Families may also express anger or extreme grief or be unable to understand what is happening. Doctors face the unenviable task of explaining that some patients will not survive, while for others there will be a long road to partial recovery.

Volunteer Care Programme

ComaCARE began and remained a totally voluntary organisation for two and a half years until funding enabled the appointment of a minimum staff core. Voluntary activity in a neurosurgical intensive care unit (ICU) and high care wards is not the norm and it has been important for the organisation to respect the existing culture and work ethos.

ComaCARE trained volunteers have worked with patients and their families for a period of three

years in the neurosurgery ward and neurosurgery intensive care ward in Groote Schuur Hospital, a major teaching hospital in South Africa. The A BIT OF CARE approach is taught in a training programme and then the volunteer is accompanied on the ward until they feel comfortable working with the patients. This care involves accompaniment, counselling and physical care programmes to ensure the patient's dignity. Each volunteer visits at least once per week.

The volunteers debrief their experiences by writing a diary and attend monthly supervision for their own care.

Volunteers have additional training programmes over the course of a year, including topics such as introduction to ComaCARE, bedside care, brain trauma, death and dying and family counselling and they are recognised for their service through an acknowledgement programme.

Many coma volunteers come from the same communities as the majority of the patients and their knowledge of language and culture is of great help, especially in the patient rehabilitation process. This is also critical for the five percent of patients who arrive at the hospital unidentified as result of random violence or community attacks. Tracing their families from the confused signals and words uttered by the patient is important work for ComaCARE volunteers.

In addition to the work conducted in the neurosurgical ward, there is a dedicated team who work in the ICU and with dying patients and their grieving families.



Patient Advocates in tertiary hospitals

Due to the success of the volunteer programme, ComaCARE decided to select six volunteers per year for an intensive training programme that would last two years. These volunteers have become Patient Advocates and work part time on the wards.

The Patient Advocates are carefully supervised daily for the first three months and thereafter receive weekly supervision.

The role of the Patient Advocates involves ensuring patient dignity and the support of therapeutic activity, such as helping the occupational therapist

with passive movements, wheelchair transfers and social stimulation of brain injured patients. They also work with swallowing and speech and language issues under the guidance of the speech therapist. In addition, the Patient Advocates support the families at this stressful time.

Patient Advocates, who are paid a stipend by ComaCARE, contribute 480 hours per month to the care of patients at Groote Schuur Hospital. It is hoped that this model could be supported and replicated elsewhere in the tertiary care system.

*I feel good and curious to be a Patient Advocate because I learn and get skills and experience, while I give help and support the patient. **Nosipho***

*For me, I feel happy to be a Patient Advocate because I like to help people who are suffering. I also like to help counsel the families and patients. **Noluvuyo***

*Being a Patient Advocate means that I should back the patient by supporting, encouraging, helping a coma patient make a comeback. I give the patient bedside care, counselling, helping him to feed himself and encourage the family in his care. I am also there for the patient and family if he passes on. I am encouraged and passionate, confident and feel excited for the future – really fulfilled. **Elizabeth***

*It means a lot to me to be a Patient Advocate because I am growing myself as I get more experience about our people as patients. **Thelma***

*It means that I can communicate with confidence in front of a lot of people and I've gained lots of fun. I love doing this job. **Precious***

*To be a Patient Advocate means to be compassionate at all times. I enjoy educating my patients and their families – even at difficult times when we have to explain brain death. I am committed to stay respectful and treat my patients with dignity. It is wonderful to mean so much to patients and their families. **Olga***

In every bed could be my mother,
brother, sister or friend

HEARING THE SILENT VOICES

Many young men in the neurosurgery wards of South Africa suffer brain trauma through car accidents or violence. This young man entered a coma in a different way, but the impact on the family, as always, was profound.

ENCOURAGING HOPE WHEN ALL SEEMS LOST

God is always on your side, He will never leave.. Don't quit on me, Son.

My son, Sibongile, was born with water in his brain and had an operation at six months. Whenever the water gets blocked he stops functioning, stares emptily into space.

On 29 December, I heard him moaning from my room in the middle of the night and I rushed to where he was. He was staggering, struggling to hold on to the door handle and started throwing up. I urged him not give in, told him to hang in there while I tried to get transport to take us to hospital. A doctor at Groote Schuur told me my son was in a coma and there was nothing more they could do. He had already had nine operations. The staff introduced me to ComaCARE. I was in a state

after being told my child would not live. They [ComaCARE] encouraged me not to lose hope and assured me that they would be there to support me. They taught me how to talk to and treat a person in a coma. They taught me to always:-

- Use the same soap consistently so he could recognise me
- Touch him while talking to him softly and slowly
- Look for signs that he was hearing me and encourage him to respond in whichever way he could.

They also gave me the information pack, but it was hard for me to read it without breaking down in the first three weeks. I remembered what they had told me and I did everything they'd said.

I had to come and see him everyday and this affected my work, so I quit my job to be fully there for my son. Transport was costly and, once more, ComaCARE came through for me. They helped me and my sister with the daily transport fare to and from hospital.

I would say to him:

Son, you can't quit on me now. You haven't given me any last words. I will not give up on you. Please don't give up on you.

The nurses in the ward were also very supportive. It wasn't always easy though. At times his condition seemed to worsen and I'd flee the hospital in tears. In 2008, Sibongile was transferred to another facility while he was still in a coma. I refused to give up on him. ComaCARE continued being supportive, calling to encourage me and to check how he was doing.



The family counselling room

HEARING THE SILENT VOICES

I always said to him:

In everything, no matter where you are, God is always next to you. God will never leave nor forsake you.

Sometime in April I was talking to him and I suddenly saw his lips moving slightly. I talked to him more, asking him to squeeze my hand if he could hear me. Slowly he'd try to squeeze my hand and I knew my child was coming back to me. During my next visit his eyes were open and he would move them or blink in response. I'd ask him to smile and he would.

In June, just before his 30th birthday, he started talking. He's still not 100%, he's learning everything all over again, just like a child. We had a party for him in his ward and he was very happy. He's still forgetful at times and he forgets people who come to visit, but he never forgets his mother. I ask him

*Do you know who I am?, and he says
Of course, you're my mother. How can I forget my mother?*

ComaCARE also told me about how they could help speed up the grant if needed. However, my son had already been receiving his disability grant, but it was stopped when he was in a coma because he could not go and collect it himself.

Sibongile is hopefully coming home at the end of the month. They told me he's better, but we are still waiting for a wheelchair because they said he'll never be able to walk again. I just want him home.

I've rearranged the house, repainted and decorated his room. I'm planning to extend the bedroom so he can have privacy.

I'm very grateful to ComaCARE for all the help, the encouragement and the things they taught me. I never felt alone, they were my family. I know I can call them anytime.

Today I can educate other people whose relatives are in a coma. The boy who sleeps next to my son in hospital was also in a coma and the family was always crying. I called the mother to the side and comforted her, telling her she should not cry at his bedside. I tell them my child's story and how he came through. I taught her things I learnt from ComaCARE and by the end of our talk she felt so much better.

Another family expresses their gratitude:

*Thank you COMACARE for
your continued support.
Nenze njalo nakwabanye!
(Please continue doing
the good work for others).
If your services can be
extended to other public
hospitals, a lot of people
in coma and other hospitals
would be helped.*

If I am right and you are wrong,
we are both wrong

ADVOCACY PROGRAMME

Advocacy usually means standing behind or alongside someone to help them express their views, needs and dreams to those in power. It implies support, encouragement and backing. It does not make one party wrong, guilty or oppressed.

Visibility

To stand alongside and be a witness is extremely important for coma patients and families who have slipped off the radar of possibility and do not necessarily have the resources to express themselves clearly. To make coma patients visible, ComaCARE maintains a presence on the wards, writes articles, has a website and creates awareness of this mysterious state.

Easier access to existing resources

However, visibility is not enough. We have begun to develop care protocols that will improve the socio-economic conditions of coma patients. Too often families face financial stress because of the additional burden of travelling to hospitals and then paying for special care needs when they return home. To get grants and benefits that are

available can take many trips to different specialists. Now, there is an 'easy access clinic' in Groote Schuur Hospital for patients and their families, where the patient can be seen and assessed by therapists, a Brain Injury Group counsellor and ComaCARE staff.



This team helps the patient get the relevant documentation ready for a monthly visit from the South African Social Security Agency (SASSA), who were invited by ComaCARE to join the service to ensure easier relief from financial stress. This is an excellent example of a collaborative response to patient and family needs.

A screenshot of the ComaCARE website. The header features the ComaCARE logo, which consists of a circular emblem with wavy lines and the text 'COMA CARE' and 'HEARING THE SILENT VOICES'. Below the logo is a 'QUICK HELP' button. The main content area includes the text 'A coma patient is an expert in altered states of consciousness.' and 'Information about brain injury and coma'. There are also buttons for 'SUBSCRIBE TO NEWS' and 'PROJECTS'. At the bottom left, there are navigation links for 'Home' and 'About us'.

ADVOCACY PROGRAMME

Knowledge of existing resources

ComaCARE has developed a pack of information which explains coma and ComaCARE techniques, minor brain injuries, how to access a support group, how to welcome a brain injured individual home and which grants and benefits are available for patients and care givers. These brochures are available in isiXhosa, Afrikaans and English. ComaCARE has developed a leaflet explaining brain death and a leaflet to help family members know what to do when someone dies in hospital.

Creating bridges for communication

ComaCARE is currently developing picture cards which explain the most common reasons for traumatic brain injury and coma. Keywords are translated into Afrikaans and isiXhosa to help medical practitioners explain the situation of the coma patient and their treatment to distressed families.

Families often cannot 'take in' what is being said and we hope that a picture will help them engage in the conversation, although we know that high levels of stress make it difficult.



All our advocacy work is based on research conducted with coma patients and their care givers. Therefore, solutions suggested for policy and protocol development are practical and implementable.



I had the opportunity today at the clinic to meet some of the patients and families who have been to the clinic previously.

The result of an on-the-spot survey was a unanimous, unequivocal thumbs up. People are very happy with the clinic.

Things they appreciate:

- They didn't have to make several separate journeys to see the various disciplines;*
- They understand the rehabilitation process better;*
- They now know what each discipline is about and has to offer;*
- They have more insight into coping/communicating with their brain injured relatives;*
- They know how to modify their responses to a family member who is difficult to live with at times.*

Thanks to everyone for working with the clinic so far, it is making a difference!

Sally Rothemeyer, neurosurgeon.

**We have chosen to be involved,
to appreciate, to honour, to care
from within the public health system**

RESEARCH PROGRAMME

ComaCARE is working in a pioneering field and as such must be aware of current research about coma, its care and its impact. We are also aware that as innovators we need to be conscious of all we do: testing the validity of our integrated methods. We do not believe that any patient can be cared for in isolation. Therefore our integrated methods mean that research is conducted about those both in and around the bed, the society from which they come and to which they will return, their belief systems and world view, their survival and development strategies and responses.

The breadth of our work also means that research is challenging – it does not easily fit into randomised control trials of a single variable, nor would we want it to.

Observation is probably the simplest form of research and often overlooked as a method. At ComaCARE we observe very closely what works in relation to patient care, how families react to stress points in the care system and adjust our response accordingly.

In 2006 we hosted two international researchers from the Netherlands. They conducted five months' research on the "coma path" of 100 coma patients at Groote Schuur Hospital, Red Cross Children's War

Memorial Hospital and Conradie Care Centre. The research of Niejenhuis and de Vetten (2006) still informs ComaCARE's programme development.

They state clearly:

"ComaCARE can help in developing leaflets, protocols and educational programmes about coma for volunteers and professionals.

ComaCARE should seek integration with existing staff through multi-disciplinary ward rounds and

in the rehabilitation phase be involved in patient stimulation.

Finally, ComaCARE volunteers can play an important role in dealing with families. It might be possible that they act as an intermediary between medical staff and families so that communication can be more efficient."



Since that report, we have acted on the recommendations. We are now members of the multi-disciplinary team, have developed a family pack of information brochures, counsel families at the bedside, train care givers at all levels, have developed the Patient Advocate role to provide that vital bridge and are developing care protocols. Clearly research is a driving force in our work.

RESEARCH PROGRAMME

Since 2006 we have supervised other researchers and from their studies have learned more of cross-cultural care, the needs of unidentified patients, family members' understanding of coma and consciousness, team work in high care settings, brain death and its impact on care givers.

In 2008 ComaCARE launched an ambitious project to assess the impact of the ComaCARE approach on patients, families and care givers. Thirty medical staff were interviewed and took part in a compassion fatigue scale self assessment before and after ComaCARE training was conducted. Families and patients were also invited to take part in this study to find out if the existing services really were optimal in their support. The results of this research will continue to inform our programme development and our future lobbying strategies.

Archbishop Desmond Tutu defined a person with Ubuntu as open and available to others, affirming of others, one who does not feel threatened that others are able and good; for she/he has a proper self-assurance that comes from knowing that he or she belongs in a greater whole and is diminished when others are humiliated or diminished. Ubuntu is the fact that you cannot exist as a human being in isolation. ComaCARE has displayed this philosophy in spades in their day to day actions to alleviate the suffering of patients in this hospital. This NPO is continuing the very noble and patriotic tradition of South Africa as a leader of research – their research is quite revolutionary.

Glen Takeloo



Thandiwe is the researcher at ComaCARE

Volunteers are strengthened when they are recruited from existing social networks – each one, recruit two!

EDUCATION PROGRAMME

Education usually means experts and a knowledge base. In ComaCARE, education means opening doors and asking new questions. Through this simple process we test our assumptions about the way we see the world. Therefore, our education allows space for exploration.



Volunteer training and supervision

We are developing a model of volunteer intervention in a high care and ICU environment. At present we have identified the need for two teams of volunteers. One team

specialises in ICU care and supporting the dying patient and their family, the other focusses on the the issues of recovery and rehabilitation in a neurosurgery ward.

The basic volunteer training programme includes:

- Introduction to the evolving ComaCARE approach.
- Bedside Care.
- The impact of brain trauma on the patient and family.
- Patient and family counselling.
- The death and dying process.

It is necessary that all volunteers are supported with supervision on a regular basis to ensure they are able to debrief after stressful times with patients and to ensure we capture the valuable lessons we are learning.

Since 2005 ComaCARE has trained over seventy volunteers including 10 hospice and 10 cancer care counsellors.

We are also working collaboratively with the hospital pastoral care team whom we train and we welcome their interns who seek experience in this field.

Patient Advocate Training

ComaCARE has developed the unique role of Patient Advocates. The P.A.s work twenty hours per week in the high care, ICU and rehabilitation wards of the neurosurgery unit.

These dedicated women are being trained over a two year period in all aspects of patient's care and how to support therapeutic interventions under the guidance of professionals.

For the first three months they are supervised daily and thereafter weekly. It is hoped that after two years they will be able to gain employment as specialised care givers. ComaCARE is thus supporting job creation in the field of care giving.



One Pastoral Care trained volunteer explains his experience below:

My experience of being in ComaCARE for the past few weeks has been challenging in the sense that it was my first time to be close to people who are in a coma. I felt so empowered being given the opportunity to be here, to realise that these patients are able to communicate even though they are in a coma. I also had a great experience of hospitality and welcoming from the staff members of ComaCARE. There is a great sense of ownership and love in their ministry and also a community spirit that is among each one of its members.

Bruce Mwenda – Pastoral Care Trainee, Zimbabwe

EDUCATION PROGRAMME

Nurse training programme

ComaCARE developed two levels of non-certified nurse training.

Level One training for nurses includes understanding the coma state, the impact of brain injury, empathy with a coma patient, understanding diversity and ensuring nurses appreciate the need for self care.



This two day programme has now been attended by 47 nurses from the Western and Southern Cape.

A wonderful graduation ceremony congratulated the nurses on completing their studies and assignments and encouraged them to study further. A four day Level Two training will be offered to nurses in September 2009.



Post Graduate Diploma in Nursing

ComaCARE, the Division of Neurosurgery at Groote Schuur Hospital and the Division of Nursing and Midwifery at the University of Cape Town, are collaborating to develop a new specialist programme in neuroscience nursing. This is an exciting development and is in response to the fact that 90% of discoveries in neuroscience have taken place in the last fifteen years and nurses need to be equipped to cope with this challenge.

We feel honoured to be in this partnership.

In terms of skills transfer, ComaCARE has done a tremendous job. They have trained nurses and volunteers in the care of coma patients and this specialist knowledge has brought about a change in the treatment of coma patients. Patients are not referred to by their condition, but by their names. Heart has come back to the care profession.

Thanks to ComaCARE!

Nurse in neurosurgery



The ComaCARE badge sits proudly on the lapel of a well trained neurosurgery sister

MAKING A DIFFERENCE

From its inception, ComaCARE founder members knew that only when hearts and minds are transformed, can practice change. We believe our role is to be innovative and responsive to the needs of patients, families and care givers. The Director of ComaCARE was recognised for this pioneering work when she was awarded the international Ashoka Fellowship in recognition of social entrepreneurship.

Moving hearts

Care for the care givers

ComaCARE staff and volunteers come from diverse communities. Like most South Africans, the way we think and experience the world is influenced by the legacy of the Apartheid years.

Many of our volunteers still live in areas of high poverty and crime, facing exactly the same social problems as the patients they are serving. Other volunteers and staff come from places of relative privilege and security. All of us face the challenge of working in a diverse multicultural team and we are committed to becoming the change we want to see in South Africa.

We say this humbly as we try to find a road we can all walk along together, but one of our achievements in the last four years is a commitment to find a way

forward. We have and will continue to make mistakes, but see ourselves learning from the experiences to become a more conscious organisation.

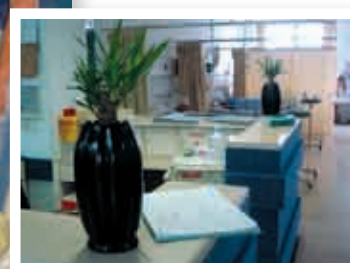
In this light, ComaCARE invited Ben Zander, Conductor of the Boston

Philharmonic Orchestra and international motivational speaker, to address the staff of Grootte Schuur Hospital and ComaCARE volunteers. In addition, we were invited to a wonderful day of joy, laughter and learning about "The Art Of Possibility". The words, "Remember rule number six" (don't take yourself too seriously!) and "Creating frameworks for possibility" still ring in our ears.

Later in the year, all ComaCARE staff and volunteers attended a "Healing of Memories" workshop where we looked at the realities and legacies of Apartheid. We listened intently while we each shared our own life journey within this history. This was an incredibly moving experience where we appreciated the vulnerabilities and strengths we bring to the care process. We have continued this work of healing ourselves with guided development days and supervision.

In the public health system, ComaCARE has set a goal of renovating spaces to provide a pleasant atmosphere for healing to take place. Last year one ward was rejuvenated and in 2009 the intensive care unit will also be renovated through a partnership of

Grootte Schuur Hospital and ComaCARE.



MAKING A DIFFERENCE

We are particularly committed to supporting the development of family counselling rooms and, in addition, ensuring that care staff know they are appreciated for their efforts.

ComaCARE sells calendars to fundraise for these interventions and the calendars themselves shift hearts and minds through their beautiful images and phrases such as "A coma patient is more than a shell".



Changing Minds

Changing minds is often about presenting new frameworks or ways of seeing the same information and from different people's points of view.

In this way, we have developed a website where we represent different opinions about coma and its care.



We are particularly pleased that very young children also have a little book which can be downloaded and read to explain what has happened to their family member.

Our five levels of training are: volunteer visitors, Patient Advocates, nurse levels one and two and the developing postgraduate course in neuroscience nursing. Participants in our training are asked "What part do I play in the patient's life?" "What inhibits me from relating to this person and his situation fully?" "How do I cope when I cannot cure, but can still care?"

When cure is no longer an option, ComaCARE volunteers accompanying dying patients, some of whom are unidentified and would otherwise die alone. We also acknowledge those who have died with a simple ceremony.



The Memory Card ceremony.



A sympathy card is also given to the grieving family and they are encouraged to phone a ComaCARE counsellor if they wish to do so.

When language creates gaps,
tenderness builds bridges

WHERE WE ARE NOW...

At ComaCARE we have learned that deep and challenging relationships are the bedrock of our existence. It helped that we had few resources when we began. This period “without” allowed us to develop an organisation that values people and their interconnectedness, respects what is already in existence and seeks to add value.

Now we feel confident that we can ensure that those who join us can be in true partnership with us. We have much to learn, but from developing this model we also have experiences to share.

The figures below do not reveal the heart of our work or the mindfulness in which we try to operate...they are indicators of the opportunities we have had to learn, serve and to deepen the emerging practice of ComaCARE.

- 2355 bedside visits with coma patients
- 530 hours bedside presence per month
- 1080 patients and families counselled

- 47 nurses trained
- 70 volunteers trained and supervised
- 6 Patient Advocates trained

- 15 research projects supervised

- 400 website hits per month
- 1 500 information packs in 3 languages distributed

An independent evaluation* conducted in 2008 states:

- The culture of ComaCARE is open and transparent.
- The marketing, publicity and branding of the Trust are of the highest calibre.
- The programmes have ensured that coma is more broadly understood as an altered state of consciousness – this has had a major impact on the care of patients in coma.
- ComaCARE has managed its finances outstandingly. Rigorous financial administration and accounting processes are in place.

It ends:

“ComaCARE is a fledgling pioneering organisation which has been in existence for only three years. During two of these, the organisation had no external funding and therefore when read in context, their achievements in such a short time speak to the effectiveness of the organisation’s Board and management. Their approach to care, their tenacity, foresight and nation building attitude will ensure that ComaCARE will make even greater strides in the future.”

* Mthente Research and Consulting Services and Impact Consulting

...AND THE WAY AHEAD

We invite you to join us as we face a new era of challenge and give thanks to all those who have contributed to our development.

Hospitals being cared for by the community

Hospitals are a valuable resource in any community. Those who work there, labour for long hours in difficult circumstances. At ComaCARE we call on the community to be part of the solution by encouraging volunteer activity in OUR hospital and care facilities. Community groups have offered toiletries, entertainment, renovations and being involved in Governance structures.

We call on you to join this movement of ensuring hospitals are healing spaces for all!

The patient advocate model

In the next phase of our development we want to expand the role of patient advocate within the public health system and ensure that their training programmes are accredited through the appropriate qualifications framework.

This will make visible and acknowledge the skills base resident in community volunteers. ComaCARE also intends to develop our information strategy in local languages to assist doctors explain the condition of the patient to his family member.

This will ensure a bridge between medical staff and family members!

Professional development

ComaCARE will continue to support the development of training courses to ensure well researched and empathic care of comatose patients by all levels of care giver.

To spread our wings

In the next five years ComaCARE will have made a continental impact through its nurse training programmes and be working in other care facilities.

Join us in this exciting and humbling journey!

ComaCARE has enhanced our service in many different ways, transforming lives and attitudes. With all the stresses of a busy clinical department, we seldom manage to do all the things that matter – the time the volunteers spend talking to our patients and their families is much appreciated, complementing our care with their concern and insight. Practical assistance, such as brightening the hospital environment, helping patients secure grants and providing useful information speaks volumes for their commitment to making a real difference. ComaCARE has helped us all, neurosurgeons, nurses and therapists, to fully appreciate the difference we make in people's lives.

Graham Fieggen

Helen and Morris Mauberger Professor of Neurosurgery and Head of the Division of Neurosurgery



Only share the essence

THANK YOU

ComaCARE Trust

EXECUTIVE COMMITTEE

Dr. Reno Morar Chairperson (2005 – May 2009)
Treasurer Advisor to the Dean of the
Health Science Faculty,
University of Cape Town

Mr. Chris Giles Psychologist
Current Chairperson

Mr. Lungi Hlakudi Social Work Manager
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Ms. Jan Webster Director

MEMBERS

Ms Ann Jacob, Coma Counsellor (Canada)

Dr. Sally Rothemeyer Neurosurgeon

Mr. Eric Bafo Young Men's Leadership and
HIV/ AIDS counsellor,
family member

Mr. George Petros Senior Researcher,
family member

Mrs. Nicki Van Reenen Retired public relations lecturer

Professor Allan Taylor Neurosurgeon

Mr. Stan Tomandl Coma Counsellor (Canada)

With thanks to those who have helped govern the new initiative in the first three years

Ms. Jo MacRobert (2005-2009), Lawyer

Mrs. Dimakatso Morobi (2007-2008), MP, family member

Ms. Kobie Coetzee, Nurse Educator (2005-2009)

Mrs. Azeza Govind, Financial Manager (2005- 2007)
now our Accountant

Ms. Emily Mokoena-Mati, Film Director (2005-2008)

Ms. Colleen Marco, Oncology Specialist (2006-2007)

Mr. John Cullom, coma survivor, deceased

Funding partners

Norwegian Centre for Human Rights

Nussbaum Foundation

The D.G. Murray Trust

(also supported the Volunteers Christmas party 2008)

Our generous donors and friends:

The Cullom Family

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Prospur Pharmacy

SBH Fabrics, Salt River

Starke Ayres

Team Revolution

Toyota, Athlone

Woolworths, Cavendish Square



When you fix, you assume something is broken.

When you help, you see the person as weak.

But when you serve, you see the person as intrinsically whole.

You create a relationship in which both parties gain.

The purpose of love is to serve.

Adapted from Frank Ostaseski





ComaCARE Trust, Neurosurgery Ward F7, Groote Schuur Hospital, Observatory 7925
086 011 0111 • admin@comacare.com • www.comacare.com