



# **PATIENTS AS PARTNERS**

Brought to you by The South African Depression and Anxiety Group

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## When pain stifles your sleep

Wide awake again? Have you been tossing and turning? Maybe you can't fall asleep or you wake up in the middle of the night and can't go back to sleep? While you're certainly not alone if you suffer from symptoms of insomnia, if you have a chronic pain condition, your insomnia may be a nightly issue rather than a transient irritation. According to sleep experts, two out of three people with chronic pain conditions have trouble sleeping.

One underlying cause for insomnia is pain. Whether it's a sore lower back or throbbing toothache, pain is difficult enough to cope with during the day, but pain at night robs you of sleep and can be exhausting. Bedtime should allow the distractions of the day to drop away. It should be a time to relax and unwind, but for a person living with chronic pain, it is unavoidable time alone with the pain that may have been masked during the day. At night, the pain is amplified because it's the only activity felt by the brain. This generally makes falling asleep fraught with difficulty. Chronic pain often results in chronic sleep disturbance (chronic insomnia), which lasts for longer than three weeks and can seriously affect your daily functioning. Disturbance in sleep leads to mood changes, difficulty concentrating and decreased productivity. The problem becomes even more complicated because commonly prescribed pain medications can interrupt sleep.

An individual in pain simply cannot get comfortable enough to fall asleep, but the pain also results in difficulty staying asleep. And once pain keeps you awake one night, it is likely to do the same thing again and again. "Pain-related insomnia gets worse over time," says sleep expert, Dr Alison Bentley. Many types of pain can interrupt sleep, from the chronic pain of arthritis to the acute pain that follows surgery. The major causes of sleep loss due to pain are back pain, headaches, facial pain caused by temporomandibular joint (TMJ) syndrome, musculoskeletal pain, which includes arthritis and fibromyalgia, as well as premenstrual cramping. Pain from cancer, the disease itself and its treatment, is also a major offender in causing poor sleep. Waking up throughout the night, having difficulty falling asleep, awakening too early in the morning and generally experiencing non-refreshing sleep are all common in chronic pain sufferers.

Ultimately, all of this creates a vicious cycle. Pain triggers poor sleep. Someone experiencing lower back pain, for example, may experience several micro-arousals every hour of the night – changes to a lighter stage of sleep, which leads to awakenings. While not noticed in the pain-free person, even the slightest change of environment during sleep can wake up a person in pain. Pain is a serious interruption to sleep and is frequently associated with insomnia. One problem can aggravate the other and can be hard to treat. "When a chronic pain sufferer experiences fragmented sleep, a vicious cycle ensues," says Dr Bentley. "Sleep disruption caused by chronic pain exaggerates the pain, which in turn also interrupts sleep. This can become a pattern that is hard to break."

Dr Bentley explains how it works – we all need a certain amount of each stage of sleep to feel rested. This is our light sleep, deep sleep and REM (rapid eye movement) sleep. While we usually go through four to six cycles of these stages per night, pain means that we are constantly woken up and therefore spend too much time in light sleep. To add to the problem, shortened REM sleep may actually increase our sensitivity to pain. Some pain, like orthopaedic or arthritis pain, stops us getting comfortable – when we move, it hurts and we wake up. Research has shown that pain after surgery and other pain affects both the length and quality of sleep. In people with fibromyalgia, a chronic condition that causes joint and muscle pain, there are constant bursts of 'awake' brain activity, which prevents deep sleep so people with the conditions wake up more often during the night. "Pain is a sensation you feel when nerves are intensely stimulated. This stimulation activates the brain, which keeps you awake," says Dr Bentley.

The first step to managing your sleep disturbance is to reduce the pain. Pain control not only makes sleeping easier, but also reduces anxiety and depression. Always tell your doctor about the sleep problems you're having as a result of your pain – a change in medication may be needed. It is time to seek professional help when pain causes sleep problems two to three times a night, and you are unable to fall asleep again. There are a variety of treatments available to ease the sleep problems of chronic pain sufferers, including medication and physical therapy. There are also a number of sleep labs and sleep clinics countrywide, which offer diagnostic sleep studies.

While sleep is one of the keys to physical and emotional wellness, chronic pain can grind down emotions and whittle away our sleep, leaving us feeling raw and frustrated. But living with a chronic pain condition, doesn't always mean living with sleep deprivation.

**Call SADAG's Sanofi Aventis Sleep Disorders Helpline on 0800 SLEEPY/753 379 and get ready for some down time.**

### **SOME TIPS FOR PEOPLE LIVING WITH CHRONIC PAIN**

- Stop caffeine consumption.
- Limit alcohol intake, with no alcohol in the evenings.
- Avoid vigorous exercise. However, light exercise in the afternoon can be helpful.
- Take a brief nap in the afternoon, no more than 10 to 20 minutes.
- Painkillers and/or sleeping pills can be effective, but should be used under the supervision of a physician.
- Practice relaxation techniques, such as deep abdominal breathing.



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## Suicide, and the ones it leaves behind

by Ryan G Edmonds

*"It was a non-descriptive, rainy morning in Durban, while savouring my first cup of morning tea that the light on my mobile indicated a new message. Opening it changed my life forever. It was my partner saying goodbye, in his way – anger camouflaging his pain. Instinctively I knew that this time around I would not be able to be in time to save him. I was right. The pain of living had become too much. He felt as if he had no more choices and that suicide was the only solution left to remove the 'cancer' that was eating at his mind forever. The very moment he found liberation from this pain, I became its prisoner!"*

After her partner committed suicide, Lori Barausse started a Support Group in Durban for patients and loved ones of those affected by suicide. She shares her story after having been down a long and emotional road and now is able to share her experiences, and learnings, for those 'left behind' by suicide.

"We found it impossible to understand," says Lori. "'Why?' was the word that became our mantra. This mantra however, did not give us peace of mind – just total and utter pain. We found ourselves going through a myriad of emotions, sometimes within seconds of one another. Our lives became a rollercoaster that we could not stop."

Perhaps it is this 'Why?' question that seems to bother loved ones the most. Dr Jan Chabalala, a Pretoria-based psychiatrist, has this to say: "Often, people who have lost a loved one to suicide do not go for help. Quite a number of them, however, present with symptoms of depression a few months or years down the line. If the family members were to present for counselling, we would help them deal with the often intense and inappropriate guilt that comes with losing a loved one in that manner."

Suicide has a ripple effect on the lives of all those who loved, lived with or worked alongside the person whose life has been taken. Very often, people are left to grieve without any form of consolation, closure or professional guidance. It is so important for survivors of suicide to seek professional help, and it is usually beneficial to do so with the very doctors and therapists who worked closely with the patients themselves. Joy Chiang, herself a survivor of suicide and now also a Support Group Leader in Durban, notes how important it is for loved ones to seek professional help: "If you experience intense or unrelenting anguish, or physical problems, consider asking your doctor or mental healthcare provider for help. Seeking professional help is especially important if you think you might be depressed as a result of losing a loved one. Keep in mind that unresolved grief can turn into complicated grief, where painful emotions are so long-lasting and severe that you have trouble resuming your own life."

Dr Chabalala shares his perspective: "As soon as possible after the event, loved ones should seek the guidance of either a psychologist or psychiatrist, or any helping professional, to assist in dealing with the matter. This may help to put the death into perspective. The matter becomes more urgent if they witnessed the event." How then are psychiatrists and psychologists able to help those left behind by suicide? "It is important to educate the loved ones on the relationship between depression and suicide," advises Dr Chabalala. "The next issue would be to take them through the reactions to grief, as suicide causes complicated bereavement. Having done that, one needs to deal with the guilt experienced by the bereaved, which can be intense and, often, inappropriate."

It's generally underestimated how the death of a patient may impact the psychologist or psychiatrist who attended to them (sometimes for months or years). Therapists and doctors tend to build a strong rapport with patients, having been privy to the intimate details of their lives, and the (often sudden) passing of a patient surely affects even the most experienced of professionals. "If a patient commits suicide," continues Dr Chabalala: "you are left with a feeling of being inadequate and of having failed the patient by not having foreseen the suicide act. But, then again, a doctor's duty is to improve the quality of life, not to prevent death. No matter how trained we are on the matter, we are not very good at preventing self-inflicted death (suicide)." It is also suggested that mental health professionals assist families and loved ones, not only to help those survivors find a form of closure, but also as a way of debriefing and finding closure themselves on a personal level. Seeking the assistance of co-professionals is encouraged in cases where the impact of losing a patient to suicide is especially traumatic for the therapist.

Another key component to the recovery process has been found in the use of support groups for loved ones affected by suicide. "The grief that follows suicide is extremely difficult," says Joy. "The survivor must grieve not only the loss, but also the choice that caused the loss. Support groups offer mutual support for those who have lost a loved one through suicide. In a support group environment, we acknowledge that normal grief reactions are intensified and complicated following suicide. Support groups relieve isolation by offering the empathy of other people who have experienced the magnitude of this kind of



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loss." One person, preferring to remain anonymous, shares how the South African Depression and Anxiety Group (SADAG) assisted her in finding help: "When I called [SADAG], I felt it was my last resort. I had nowhere else to turn. A friendly, faceless voice assisted me to get in touch with a wonderful support group leader. I am now attending the support group meetings and seeing a therapist myself. I cannot describe how vital it is to seek help, and help is out there!"

It is important to note that support groups are not meant as a replacement for professional treatment. "We cannot take away your pain," says Joy. "But we can share in an atmosphere of love, acceptance and reinforcement, and direct you toward healing through this very complex grieving process. [Support groups] should not replace therapy. The healing achieved within these groups is a result of understanding, encouragement and caring among the participants." If loved ones are apprehensive about attending support groups out of fear of public ridicule or shame, Joy adds the following: "We respect the need for privacy and confidentiality. What is shared in the group stays there."

The road to healing can often be a long and painful one. There is no immediate 'quick fix' for the many emotions experienced by loved ones left behind as a result of suicide. However, with professional guidance and a strong support structure, survivors of suicide may find that they are better equipped to face the daily challenges presented by such events. "Some of us found some release in going to a support group," says Lori. "Although it did not remove the pain nor make the journey easier, it was a safe place where we were able to talk openly about our pain and our loved one, without feeling judged. Knowing that we were not alone, that similar pain was shared by others, helped us face another moment, another hour, another day. It was a way to feel human again, or just to feel."

**Lori's Support Group meets every first Monday of the month at 18:30 in Durban North and every third Monday of the month at 18:00 in Westville. Joy's group offers cellphone support and meets in Durban North at 18:30 on the first Monday of every month. For more information on getting in touch with a support group or with mental health professionals, contact SADAG on 0800 21 22 23.**

**You can also visit the SADAG website [www.sadag.org](http://www.sadag.org) for more articles and information.**

## SELF-HELP TIPS TO BEGIN THE HEALING PROCESS

1. Have a willing ear – someone who cares and can just listen.
2. No one can take away the pain, but loving support can do wonders.
3. Allow people to share good memories and experiences of the loved one.
4. Draw on resources that provide personal consolation and strength – spiritual support, religion, support groups, family, friends, etc.
5. Allow others to care for you or show concern.
6. Don't avoid speaking about the lost loved one.
7. Try and stick to a routine as much as possible.
8. Allow others to grieve with you.

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## Clarifying the role of the SAPS in mental healthcare

by Lian Taljaard

The South African Depression and Anxiety Group (SADAG), the leading advocacy and educational voice on mental health, runs a 15-line counselling call centre and is often contacted by people concerned about a loved one who is mentally ill but is not willing to seek help or is not complying with treatment. In some cases, this person poses a danger to him/herself or to others and family members are desperate to find a way to assist. This is not always easy.

Providing some direction on this issue, the Mental Health Care Act No. 17 of 2002 was promulgated in 2004 and provides guidelines for the care, treatment and rehabilitation of people who are mentally ill. Of particular interest is Section 40 of this act, which details the assistance that can be expected from the South African Police Service (SAPS) where involuntary or assisted admission into a mental healthcare facility is required.

Involuntary admission applies to people who are incapable of making informed decisions due to their mental health status, and who refuse a health intervention but require it for their protection or for the protection of others. On the other hand, when a person is not refusing treatment but is still incapable of making informed decisions about their mental health, an assisted admission may be necessary.

Earlier this year, a husband and wife from Johannesburg had to request assistance from the police to help with getting their daughter admitted into hospital. Lucy\* was diagnosed with Schizophrenia and was refusing to seek further help or treatment, so the family approached their local police station and the station commander recommended they visit the Women's Trauma Unit. Lucy's mom, Karen\*, says: "While waiting to be assisted at the unit, a detective approached us and asked if we needed any help and when we explained, he told us the SAPS don't provide this service anymore because they'd be accountable if anything should happen to our daughter during transportation." Lucy's parents were then referred to the public prosecutor at the magistrate's office, who in turn, referred them back to the SAPS. "We approached a different police station this time, but were then advised by the station commander that we need a letter from a psychologist to confirm our request," explains Karen. "Eventually, we managed to get the help we were looking for from two detectives who were familiar with involuntary and assisted admissions, and who had worked on such cases recently." Nearly a week later, the SAPS assisted Lucy's parents in getting their daughter to hospital for treatment.

SADAG's Operations Director, Cassey Chambers says: "People who are severely affected by mental illness are often not in the right state of mind to recognise just how ill they are and how dangerous their behaviour is, but it is generally at this point that an intervention is essential." Anyone concerned about a friend or a family member and needing assistance can contact SADAG from 8am to 8pm 7 days a week on the Pharma Dynamics Trauma and Police Helpline 0800 20 50 26 or visit [www.sadag.org](http://www.sadag.org) for more information.

So what can be expected of the SAPS in situations where involuntary or assisted admission into a mental healthcare facility is needed? Provincial Head of Visible Policing in Gauteng, Brigadier Naidoo says that it is an SAPS member's job to respond to any call for assistance within their appropriate jurisdiction. "As stated by the Mental Health Care Act, if a member of the SAPS has reason to believe that a person is likely to cause harm to him/herself or to someone else due to their mental health status, he/she must assist and take that person to an appropriate health establishment under the auspices of the state," says Naidoo. This also applies in instances where the protection of financial interests or the reputation of the person is affected and when the person is unable to make an informed decision on the need and willingness to receive care, treatment and rehabilitation.

According to Colonel Voyo from the SAPS legal department, an SAPS member must reach this conclusion either by their own observation or by the information from a mental health professional. "People who have private medical aid would also be taken to a public healthcare facility because the costs involved in this process are covered by government and a contractual agreement exists between the relevant state institutions. However, alternative arrangements are possible when the financial responsibility for admission into a hospital is accepted by the family," says Voyo.

If a person is involuntarily admitted into a mental healthcare facility by the SAPS, custody of that person is handed over to the head of the facility or any person designated to receive such a person, for an assessment of their mental health status. An initial assessment by a mental healthcare practitioner will be conducted within 24 hours, after which it will be decided whether the patient

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needs to be admitted into hospital or – if there's no reason to believe that the person poses a risk – released immediately.

According to the SAPS, an application for involuntary or assisted admission can be made by a spouse, next of kin, partner, associate, parent or guardian, or even a healthcare provider. If the application for involuntary admission is granted, the patient will undergo a further 72-hour assessment.

The objectives of the Mental Health Care Act are to ensure that appropriate care, treatment and rehabilitation are provided at all levels of the health service; that it effects a change from the custodial approach of the past to one that encourages community care; and that the rights of people with mental disabilities are entrenched so that they are not discriminated against, stigmatised and/or abused.<sup>1</sup>

The rate of involuntary or assisted admissions and care is widely considered to be an indicator of the level of implementation of the act. During a one-year study period, the two Mental Health Review Boards of Gauteng received a total of 3 803 applications for admissions to inpatient care, of which 66.4% were for assisted inpatient care and 33.6% for involuntary inpatient care. An additional 1 226 applications were made for outpatient care, of which approximately 92% were for assisted care.<sup>2</sup>

If you or someone you know needs help or more information on involuntarily admitting a loved one who may be a danger to him/herself or others due to a mental illness, approach your nearest police station and ask for their assistance, especially if it seems impossible or unsafe for you to get your loved one to a healthcare facility. Community members who do not receive assistance or would like to enquire in this regard may contact their local police station commanders. SADAG is also available 7 days a week from 8am to 8pm on 0800 20 50 26 for free information, counselling and referrals.

\*Name has been changed.

## References

1. Republic of South Africa. Mental Health Care Act, No 17, of 2002.
2. M Y H Moosa, MMed Psych, FC Psych, MCFP; F Y Jeenah, MMed Psych, FC Psych; Division of Psychiatry, University of the Witwatersrand, Johannesburg. A review of the applications for involuntary admissions made to the Mental Health Review Boards by institutions in Gauteng in 2008. Volume 16 No. 4 December 2010 – SAJP.

### The National Department of Health collaborated with the Directorate Mental Health and Substance Abuse to prepare training guidelines for the SAPS, which prescribe the following:

An SAPS member should suspect a person has a mental illness when...

- A family member/friend/health worker reports a past history of mental illness
- A family member/friend/health worker reports signs and symptoms of a mental illness
- A person is wandering in the streets appearing to be unable to take care of him/herself
- A person is unable to give a coherent account or is talking irrationally and displaying strange beliefs out of touch with reality
- A person is unable to take care of him/herself, is dressed strangely or is displaying abnormal behaviour
- A person is threatening to commit suicide

## IMPORTANT NUMBERS TO REMEMBER

**Suicide Crisis Line: 0800 567 567 or SMS 31393**

**Pharmadynamics Police and Trauma Line: 0800 20 50 26**

**AstraZeneca Bipolar Line: 0800 70 80 90**

**Sanofi Aventis Sleep Line: 0800-SLEEPY (0800 753 379)**

**Dept. of Social Development Substance Abuse Line: 0800 12 13 14 or SMS 32312**

**Dr Reddy's Helpline: 0800 21 22 23**

**Office Lines: 011 262 6396**

**Website: www.sadag.co.za**