Joost van der Westhuizen spends time with his son, Jordan, and his dog, Buddy, at his new home in Dainfern, a stone's throw from where his children live.

EACH DAY A BLESSING

His children have been told their Dadda is dying – but despite his frailty Joost is intent on making happy memories

By GLORIA EDWARDS Pictures: LUBA LESOLLE

HIS illness has entered another phase. Former Springbok icon Joost van der Westhuizen's daily life now involves a walking aid, a wheelchair, drinking straws and people ready to help him get around.

He doesn't drive a car any more, nor does he go out too often because it's tiring for him.

In the first phase of the motor neurone disease (MND) he was more or less able to care for himself.

But now his condition has progressed to the second phase and his quality of life has deteriorated considerably.

Have his doctors explained to him what lies ahead? "The worst," he says without hesitation.

The next phase will leave him helpless. Then he'll need a ventilator to help him to breathe. After that . . .

He has discussed all this with his children, Kylie (9) and Jordan (7).

"I've told them Dadda is probably going to be with Jesus," Joost says. "Jordan said, 'Before you go I want to come and fetch my toys'."

Joost tries to keep the tears at bay and there's pain in his smiling eyes.

His nearest and dearest have become even more important to him. He knows he's living on borrowed time and he's grateful for every day.

But night after night he dreams of escaping to open spaces with his kids and spending an entire day playing with them.

IN HIS new rented home in upmarket Dainfern in Fourways, Johannesburg, Joost descends the stairs slowly but determinedly, step by painful step.

He keeps both hands on the balustrades to maintain his balance until he reaches the bottom. Then, supported by a walking aid, he moves slowly to the couch on the veranda.

(Turn over)

Joost in his wheelchair with his close friend, Quinton van der Walt, who's at his side most of the time.

(From previous page)

The wheelchair is close at hand. He acquired it a few weeks ago for moving longer distances and for when he's in a crowd.

"My balance isn't good," he says. "If someone bumps me even lightly I'll fall. I use the walking aid here at home because I can't constantly ask others to help me." He slurs his words, as if his tongue has difficulty forming them.

He knows people find it hard to understand what he's saying. "It sounds as if I'm speaking hippo," he quips, and that familiar charming smile brightens his thin face. Fortunately his closest friend, Quinton van der Walt, is at his side almost 24 hours a day to help to interpret.

Joost coughs after almost every word and tires very quickly. Even eating has become difficult – he has lost 18 kg.

"I struggle," he says. "I can eat but it's a helluva effort."

If Quinton isn't around to cut up meat portions for him or feed him, ex-wife Amor Vittone steps in, or one of his kids will help. It's difficult for him to do the simplest tasks, such as dressing.

Joost has good and bad days, and sometimes the bad periods last longer than a day. He'd wanted to attend the recent rugby match between the Blue Bulls and the Cheetahs and accompany Amor the following night to the Ghoema awards but opted out of both.

He's still able to do a lot for himself, he says, such as texting on his cellphone, but he often needs help. "I can still drive a car but I'm not going to take a chance because my forearms are too weak."

But Joost keeps smiling.

He still has hope, he's strong, and he faithfully believes the goat serum treatment he has received from London will improve his condition.

With his breakfast he takes supplements, including vitamin B complex, magnesium and calcium. And every 12 hours Quinton injects him with the imported serum.

It's part of the AIM programme, an experimental treatment he started under the guidance of a London-based doctor about 18 months ago. He goes to London every three months for follow-up tests. "With each visit they adapt the amount of medication necessary for my body and decide when I have to take it," Joost says.

At his J9 Foundation, four levels of MND are observed in patients they deal with, he says.

Level one is the starting phase during which the muscles weaken and speech and movement are affected.

At level two, which Joost is experiencing now, patients need assistance. They lose weight and speech and movement are more severely affected.

In level three they're unable to walk or talk, have difficulty swallowing and need full-time care. Level four of the disease leaves patients bedridden and unable to breathe without the assistance of a ventilator.

But Joost's doctor says the experimental serum treatment has improved his quality of life and slowed the pace of degeneration.

"Of the 19 MND beneficiaries of the J9 Foundation, four have died and two were in a better condition than I was when I last saw them," Joost says. "Doctors initially said I would be in a wheelchair within a year but, you know what, I'm a bad loser. Only 20 per cent of MND sufferers live for five years. It's been 31 months so far."

JOOST'S eyes mist over when he talks about his children. He's moved to this house to be closer to them, he says. It's a stone's throw from their mom's house in the same security estate.

"I can't buy the house because I wouldn't get financing," he notes. "And I don't know how much longer I'll live. But since I moved in here two weeks ago they've visited Dadda every day," he adds proudly.

On the walls and tables pictures of Joost and the kids crowd out the few photographs of Joost's glory days, the rugby legend in his Springbok jersey.

A noticeably thinner Joost with his trusty walker close by. LEFT: Jordan likes giving him a hand, he says. Joost is trying to make sure his kids are provided for after his death.

Because his condition has deteriorated so rapidly he and Amor decided to explain the circumstances fully to the children. "Amor and I sat with them and she told them I was sick," he says. "She told them they had to help me – Jordan particularly likes to do things for me."

Kylie happily returns the kisses and hugs he gives them every day,

He's trying hard to make sure they'll be sufficiently provided for when he's gone.

The SA Rugby Legends Association sponsors his travel expenses but he depends on an investment policy for all his other expenses – medical treatment, maintenance for the kids, household expenses and rent.

So he has to plan for an income. Quinton manages the J9 clothing range Joost started in 1999 and they recently set up a new business within the J9 group which includes J9-Wear, a supplier of corporate outfits such as golf clothing.

The J9 Foundation shares the name of Joost's business but isn't connected to it. It's a non-profit organisation that supports MND sufferers and Joost receives no money from it.

His businesses will assist the foundation financially to ease the pressure on it and to ensure Joost's legacy, Quinton says. Joost recently moved the office of the foundation from Pretoria to his house so he wouldn't have to commute between them.

Quinton and Joost have known each other for nearly five years and have become close friends. Quinton helps to run the businesses and the household and says Joost is still very much involved.

"It's demanding work but he doesn't sit still," Quinton says. "And he travels for the foundation at least once a week. We recently returned from four fundraising efforts in Dubai and England – one was for Joost personally.

"He tries to attend all the golf days. And he's busy with meetings in his office here at home every day. His advice and knowledge lead the organisations. And he does it all for his children."

His business plans are for the kids' futures too. "I've just started putting everything in place for them," Joost says. "When I'm no longer here my trust will care for them until they're 21. They won't have to survive only on my [life] policies."

And he knows Amor will take good care of them.

AFTER years of bitter public spats with Amor and her parents Joost has a better relationship with them now. They visit one another and have talked a lot about the future, especially what to do when Joost's condition degenerates so much he can't walk or talk.

"Amor asked me to move in with her," he says. "But I'll probably have to have a full-time nurse and I don't want my children to see me like that. I want to spare them and Amor that pressure.

"That's why I decided it would be easier if I stayed on my own and my friends and family attended to me here."

His family visit often. "My mother phones me every day," Joost says. "I know she and my dad have taken it very badly. They don't talk to each other about it; it's too difficult.

"I said to them, 'If I see you so emotional all the time it makes it so much harder for me.' I don't want Mom to remember me as a grump. I said, 'We won't talk about it any more. We'll just laugh and be happy. I'm still here. Let's rather make sure we have memories that will last forever.' "

That's Joost's message to others too. "Through it all I always ask people, 'How do you want others to remember you? Now is the time to create those memories.' "

How does he want to be remembered? "As someone who cares," he replies. "I don't know how much time I have left but I actually see this illness as a blessing.

"Jordan and I sat on this couch for two hours today and talked. Then he said to me, 'Dadda, when you die I'll cry.' I told him, 'No, Jordan, you should be happy.'

"I have time to prepare. Everything is in order: my will, my faith, everything. I have time to say goodbye. I have hope. And I take things as they come." ■

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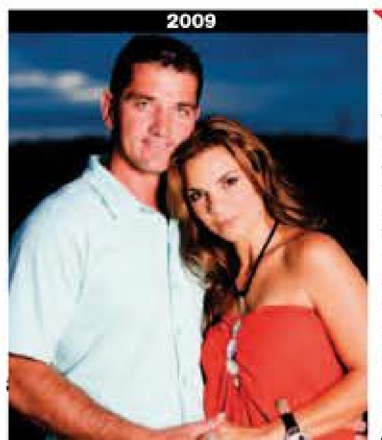

HOW JOOST HAS WEAKENED

LEFT: Joost and Amor before the rift. RIGHT: His MND was diagnosed in May 2011 and the first signs were in his hands.

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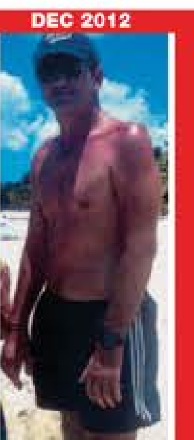

FROM LEFT: Joost at a function in July last year; he shows the scar of a rugby injury while talking about his MND treatment; pictured during a visit to the doctor; late last year at Soccer City; and during a recent family holiday.