



PERSPECTIVES FROM AN AKI SURVIVOR

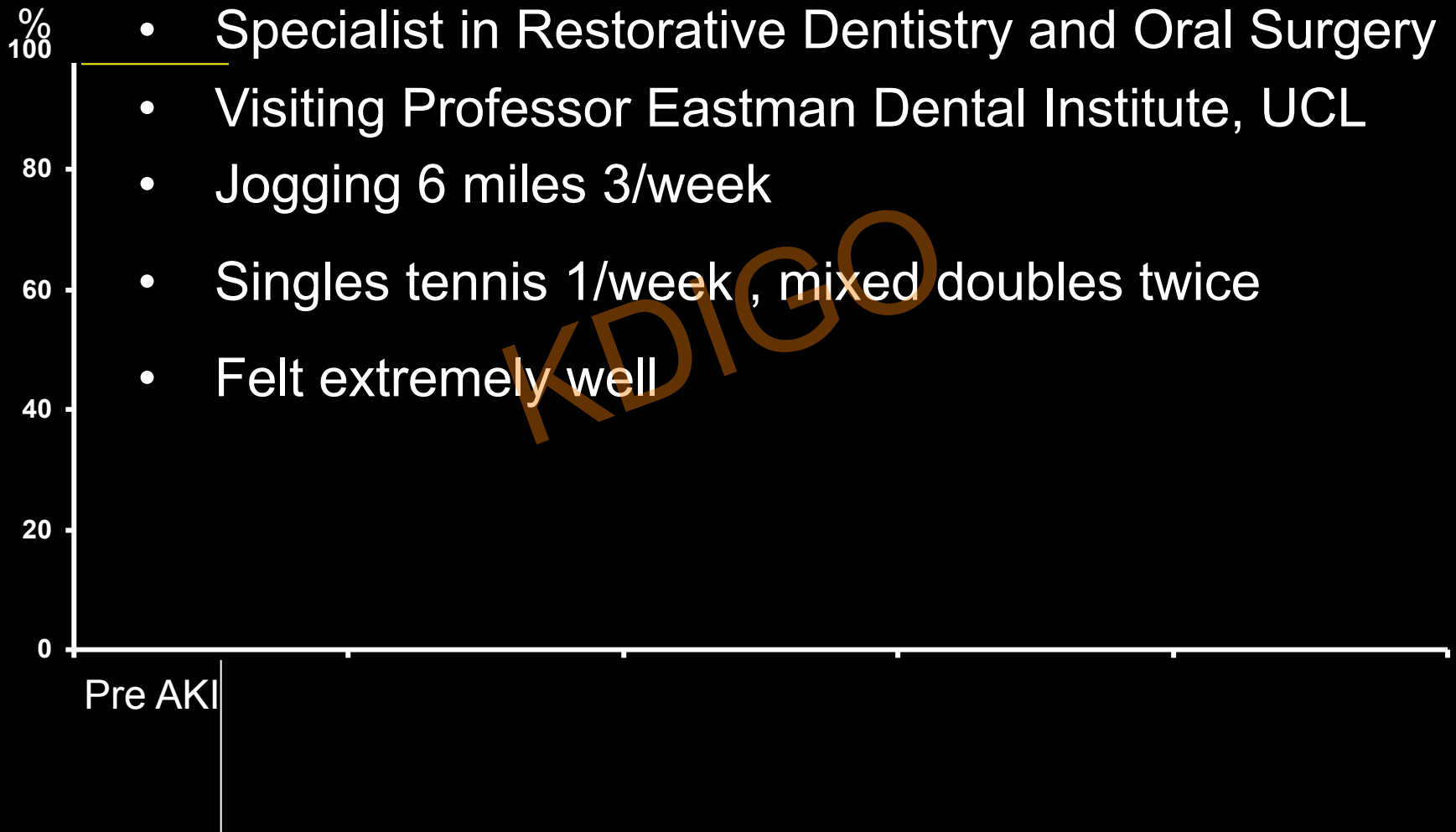
Michael Wise

Age 72

AKI III aged 62

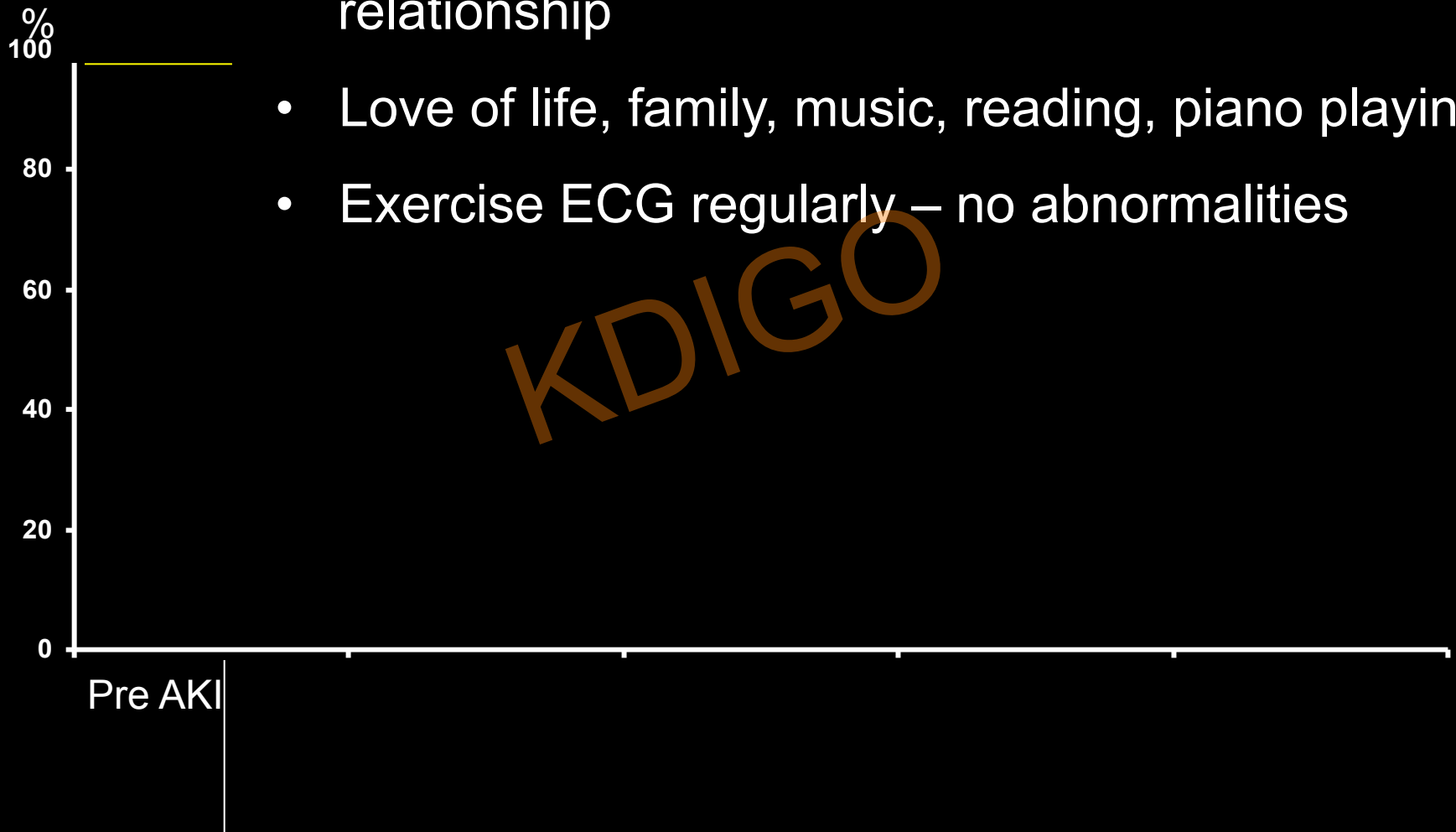
January 2009

Subjective feeling of wellness



Subjective feeling of wellness

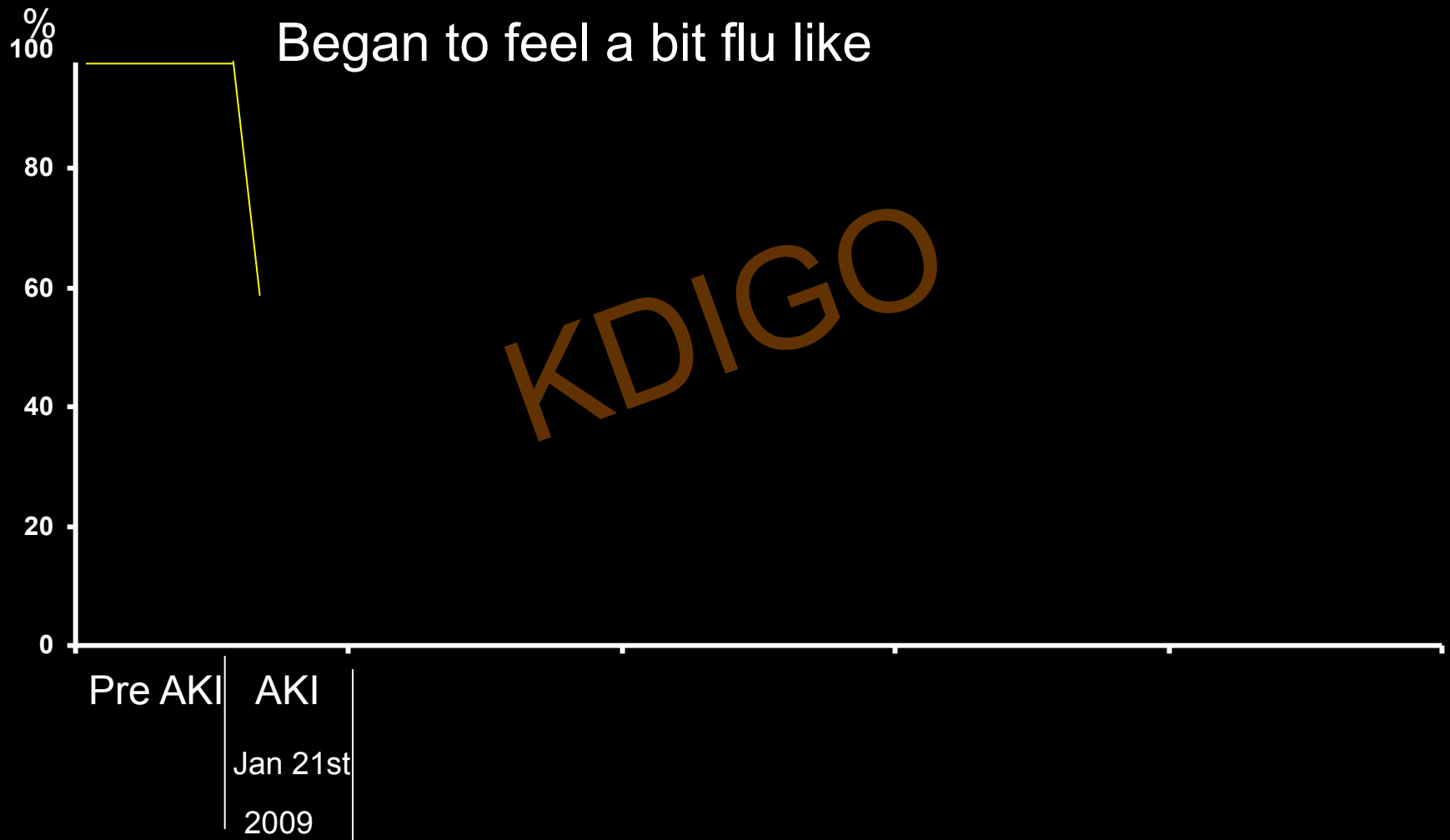
- Non problematic regular, loving sexual relationship
- Love of life, family, music, reading, piano playing
- Exercise ECG regularly – no abnormalities



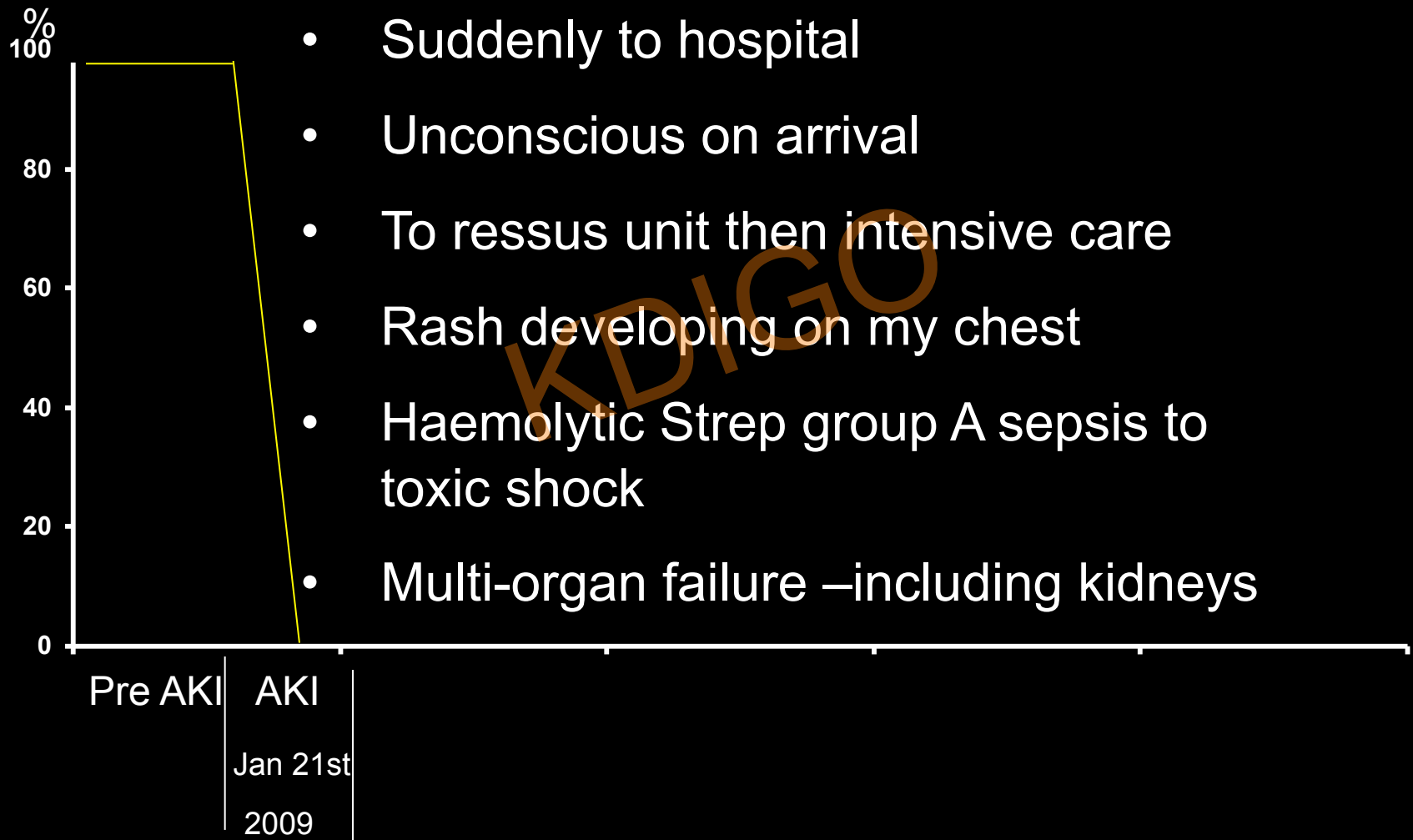
Subjective feeling of wellness

- Jan 2009 over 3 days

Began to feel a bit flu like

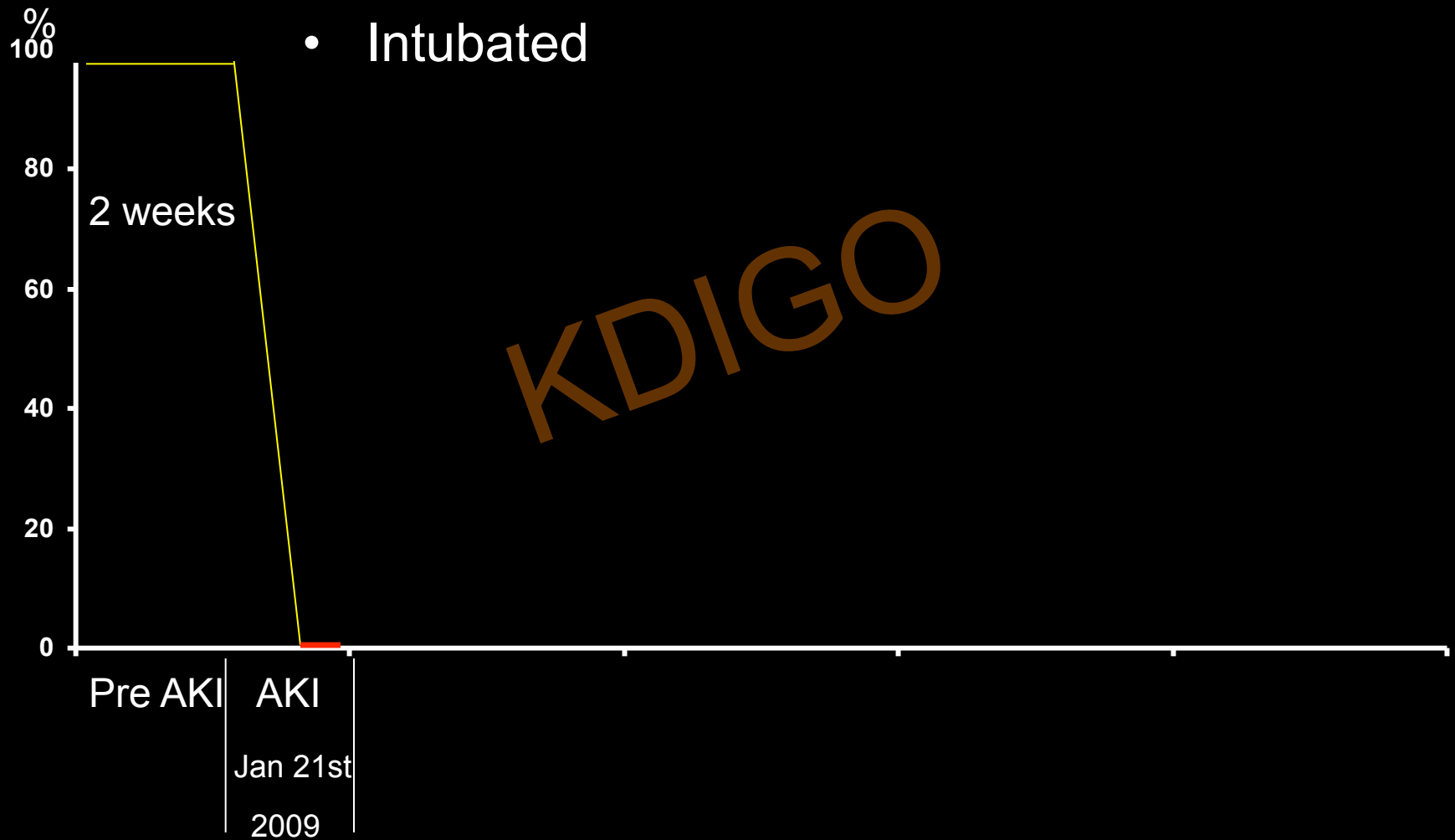


Subjective feeling of wellness



Subjective feeling of wellness

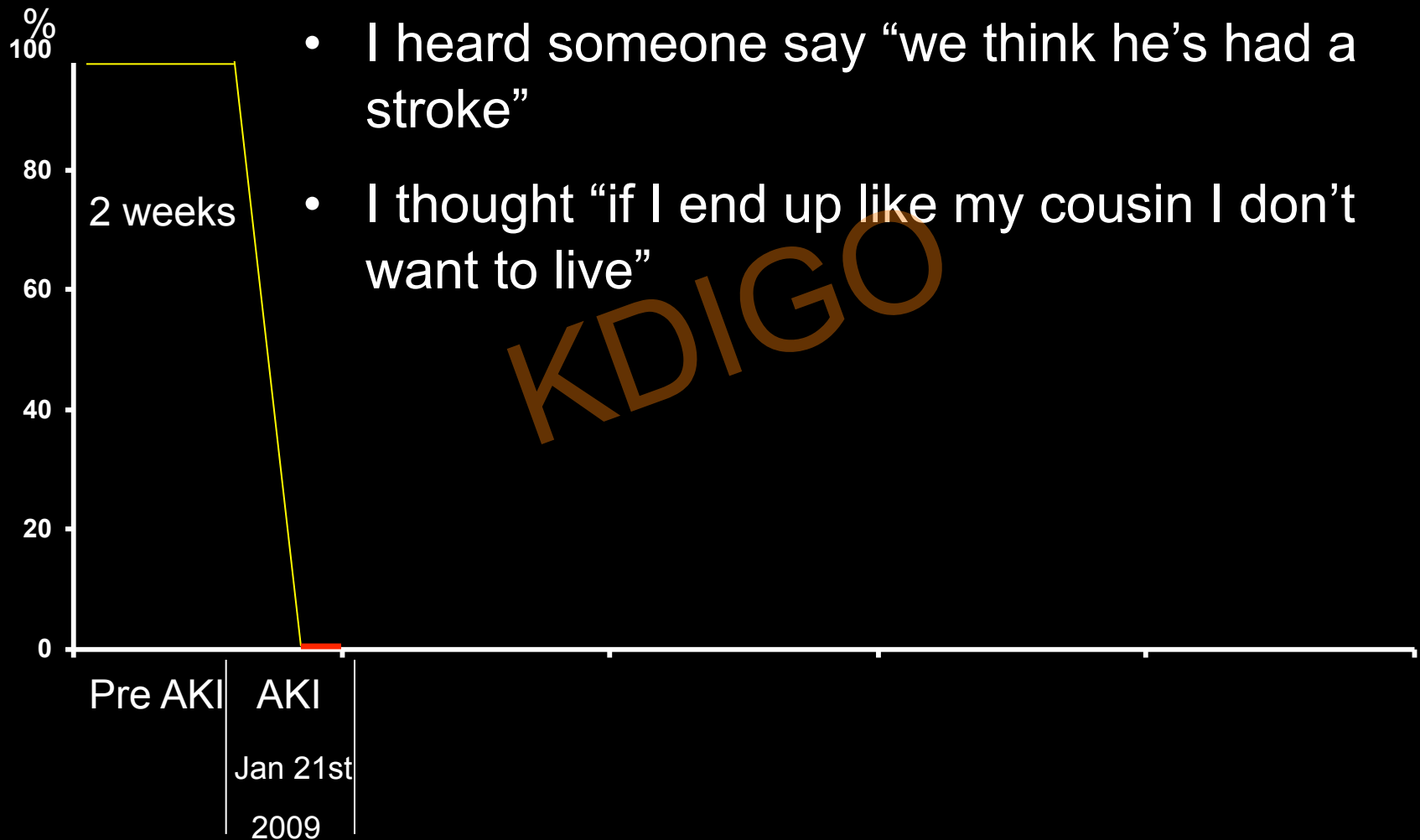
- Medically induced coma
- Intubated



Subjective feeling of wellness

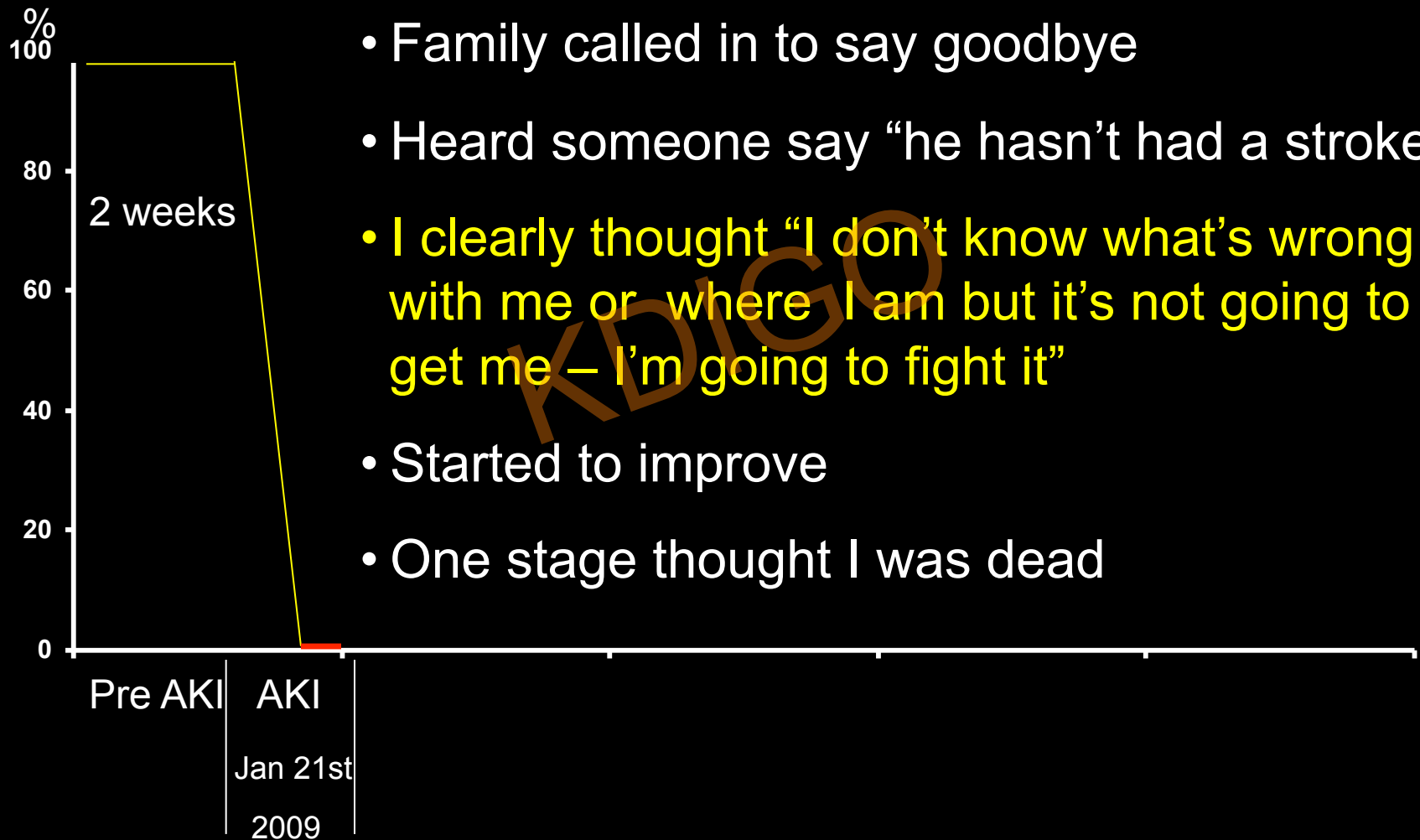
- **VERY IMPORTANT**

- I heard someone say “we think he’s had a stroke”
- I thought “if I end up like my cousin I don’t want to live”



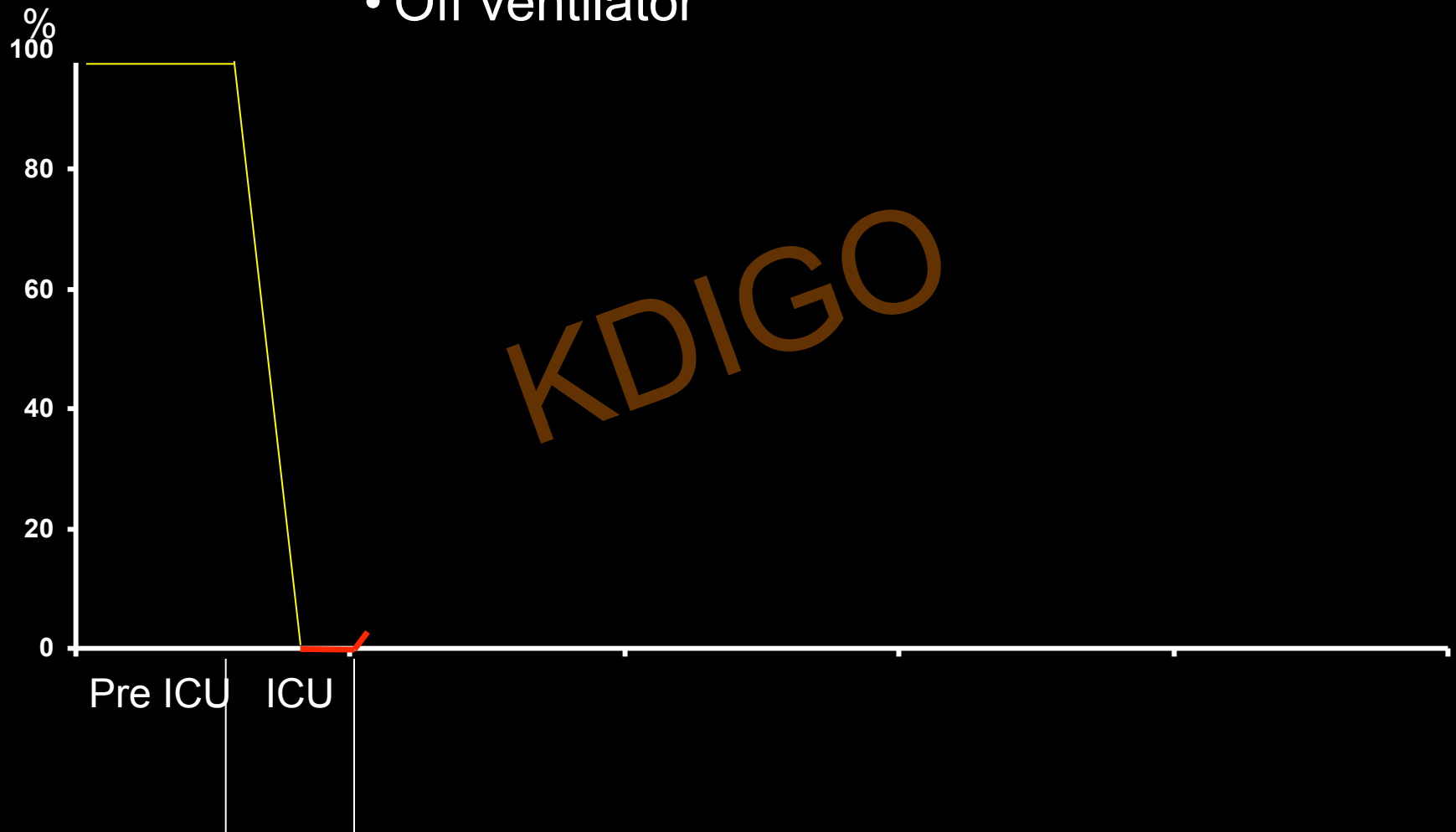
Subjective feeling of wellness

- Monitoring readings deteriorated
- Family called in to say goodbye
- Heard someone say “he hasn’t had a stroke”
- I clearly thought “I don’t know what’s wrong with me or where I am but it’s not going to get me – I’m going to fight it”
- Started to improve
- One stage thought I was dead

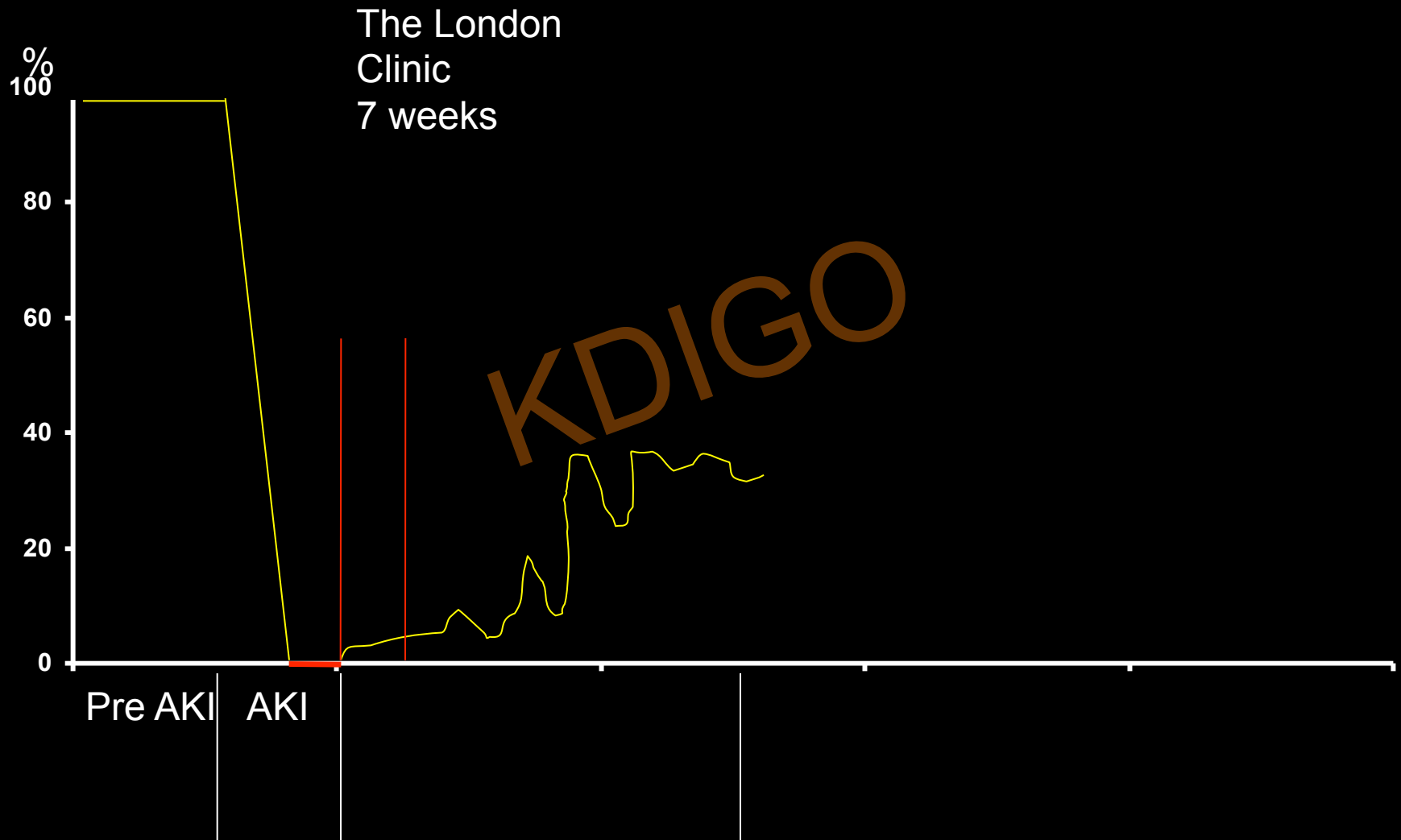


Subjective feeling of wellness

- Day 10 sedation stopped
- Off ventilator



Subjective feeling of wellness



Subjective feeling of wellness

- First 3 weeks

- Breathing
- Felt extremely unwell and weak
- Very nauseous
- Horrible itching which wasn't relieved by scratching
- Everything seemed surrealistic
- Unidimensional



Subjective feeling of wellness

- First 3 weeks

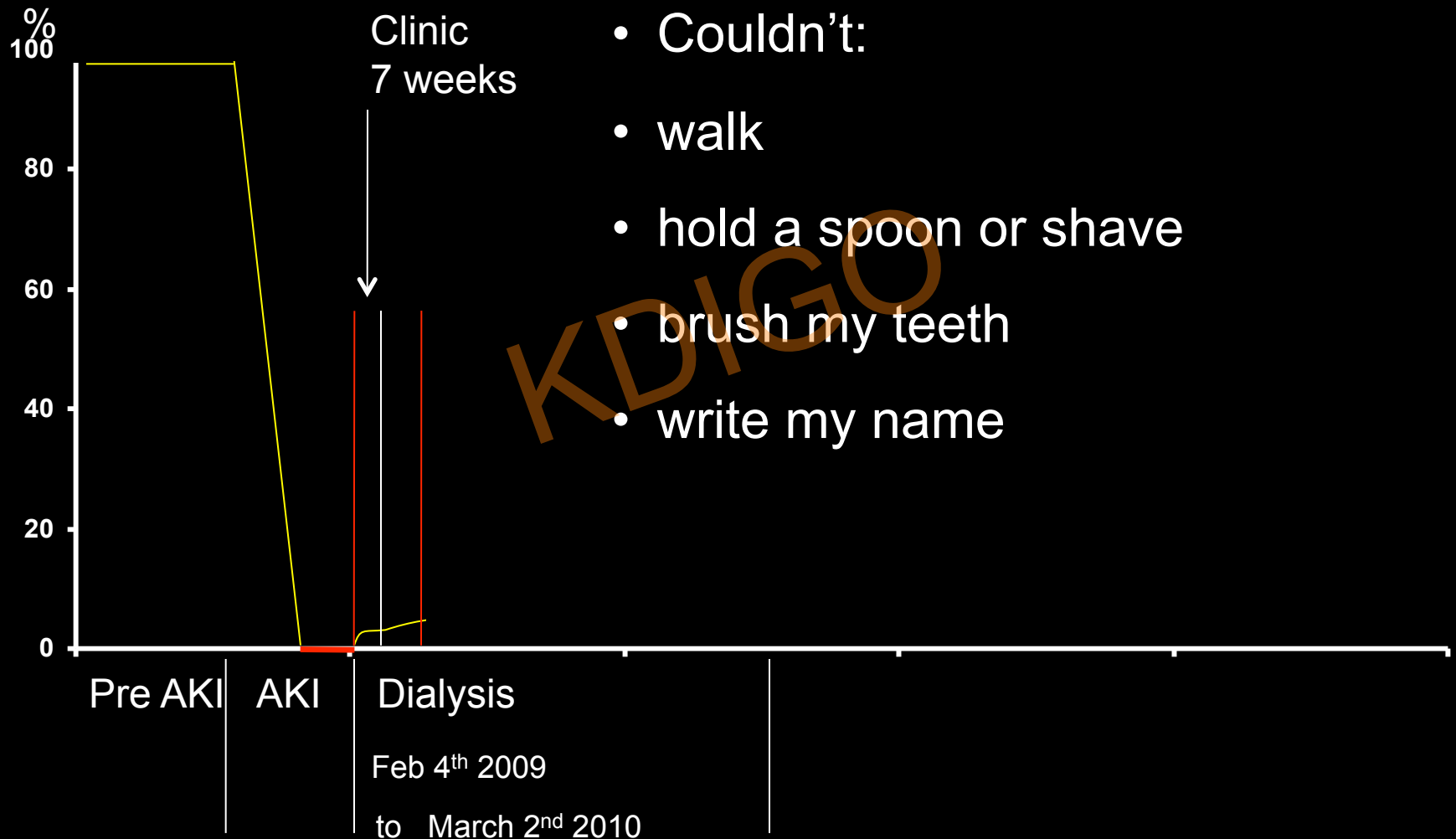
- Couldn't:

- walk

- hold a spoon or shave

- brush my teeth

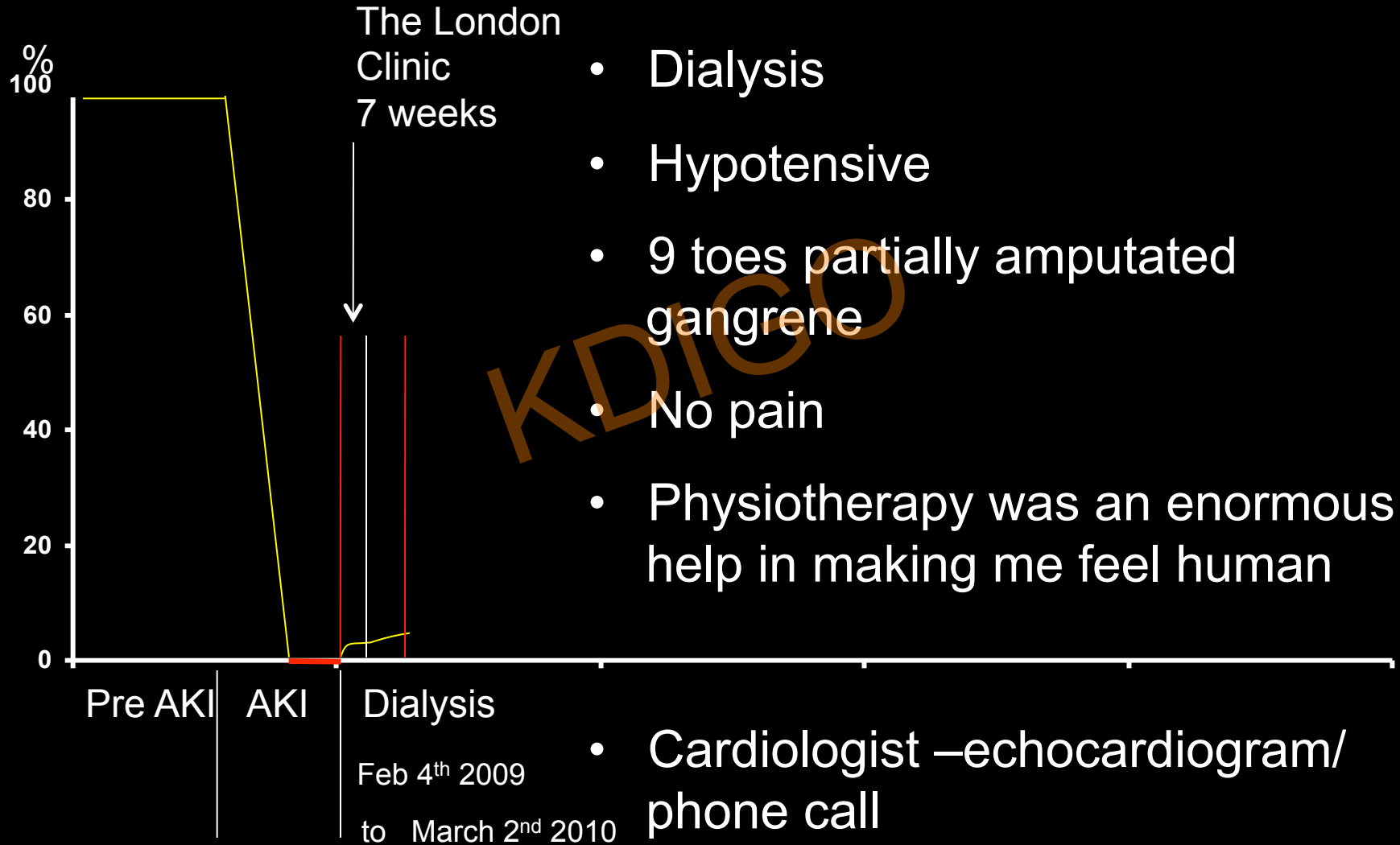
- write my name



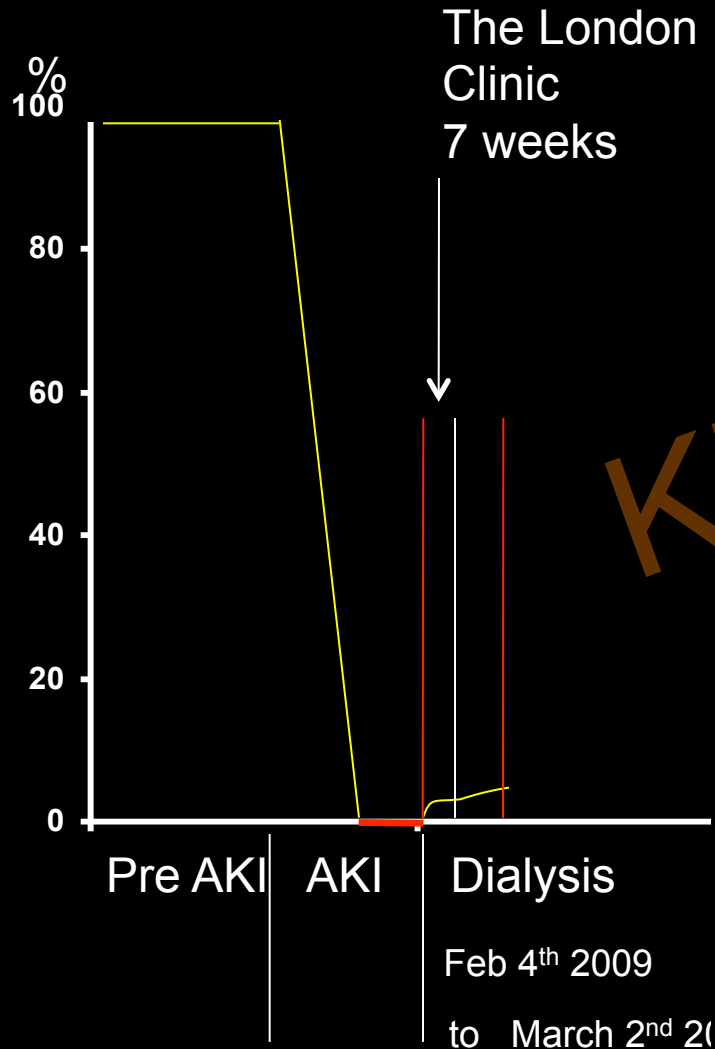
Subjective feeling of wellness

- **First 3 weeks**

- Dialysis
- Hypotensive
- 9 toes partially amputated
gangrene
- No pain
- Physiotherapy was an enormous help in making me feel human



Subjective feeling of wellness



- **First 3 weeks**
- We celebrated our 40th wedding anniversary
- Felt very positive and determined to face each stage as a challenge
- To see how I would respond to it, what was happening
- How I could most help myself and my family

Subjective feeling of wellness

- **Next 4 weeks**

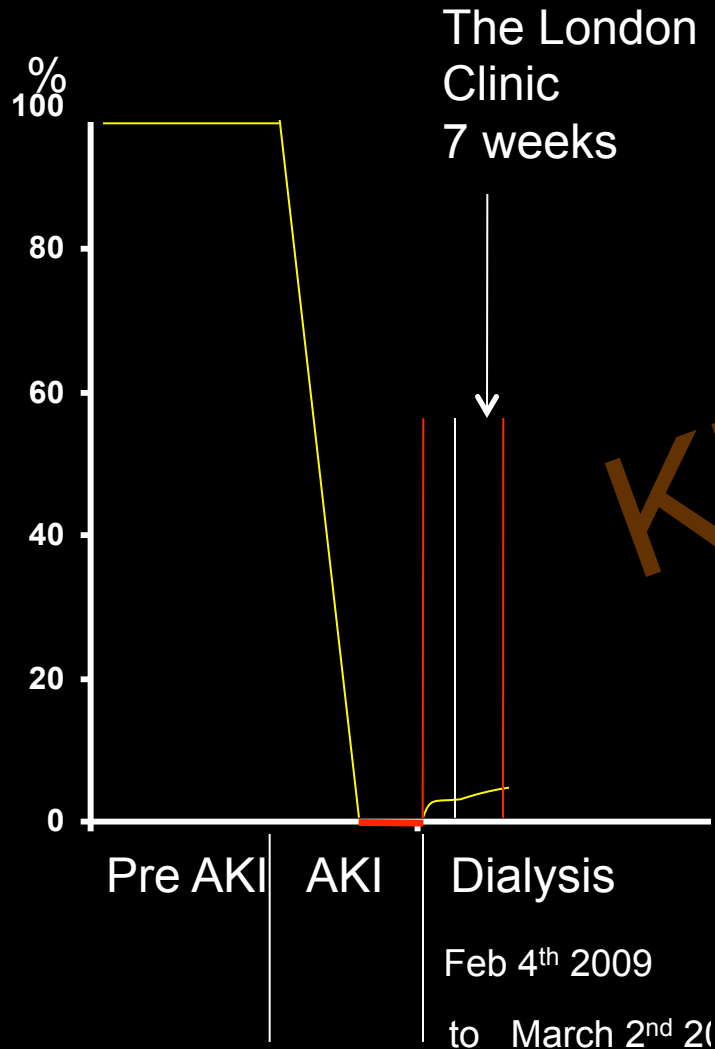
- Concern about my practice and finances

- Hope that kidney would come back – told 8 out of 9 come back

- Feeling bit better, could wash, shave not shower,

- Taken out in wheelchair – wonderful to experience normal life

- Slightly breathless at night needed oxygen



I knew what kidneys do (50% don't)

BUT

I didn't know what happens when they don't

function

KDIGO

Felt extremely unwell and weak

Nauseous

Sleepy

Itching

Difficult to concentrate

Muscle cramps in legs at night

Lost libido

KDIGO

Puffiness around eyes particularly in morning

Swollen feet and ankles

Change in taste

Stomach pain

Headache

Lower back pain below rib cage

Surrealistic

Without dialysis or transplant will die

Subjective feeling of wellness

- Discharged
- Good to be home
- Felt very unwell, nauseous, very sleepy
- Had lost :
 - health
 - vitality
 - possibly my practice
 - sexual drive

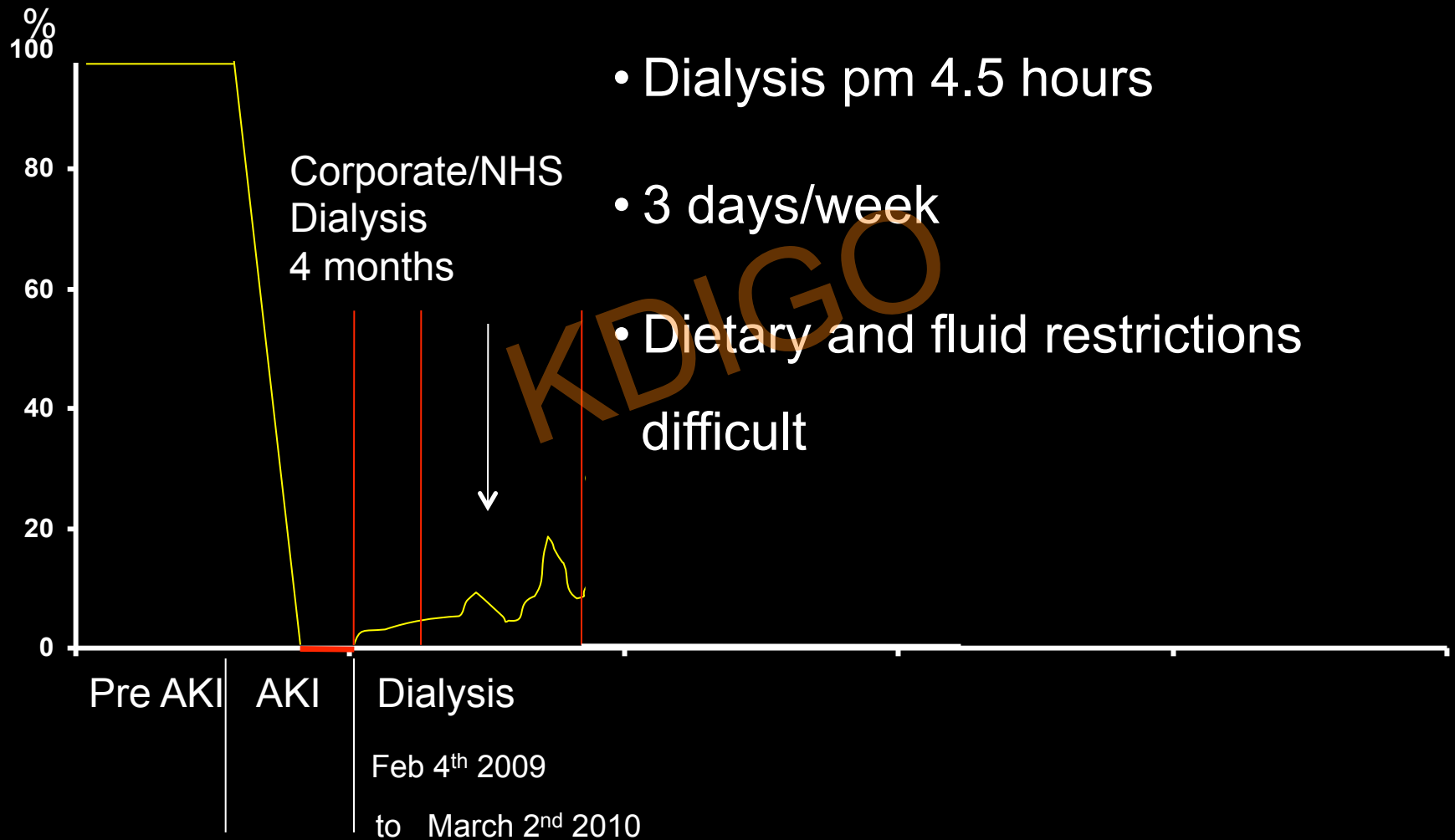


Subjective feeling of wellness

- Could not :
 - listen to music
 - play the piano
 - read
 - drink water from glass it had to be plastic



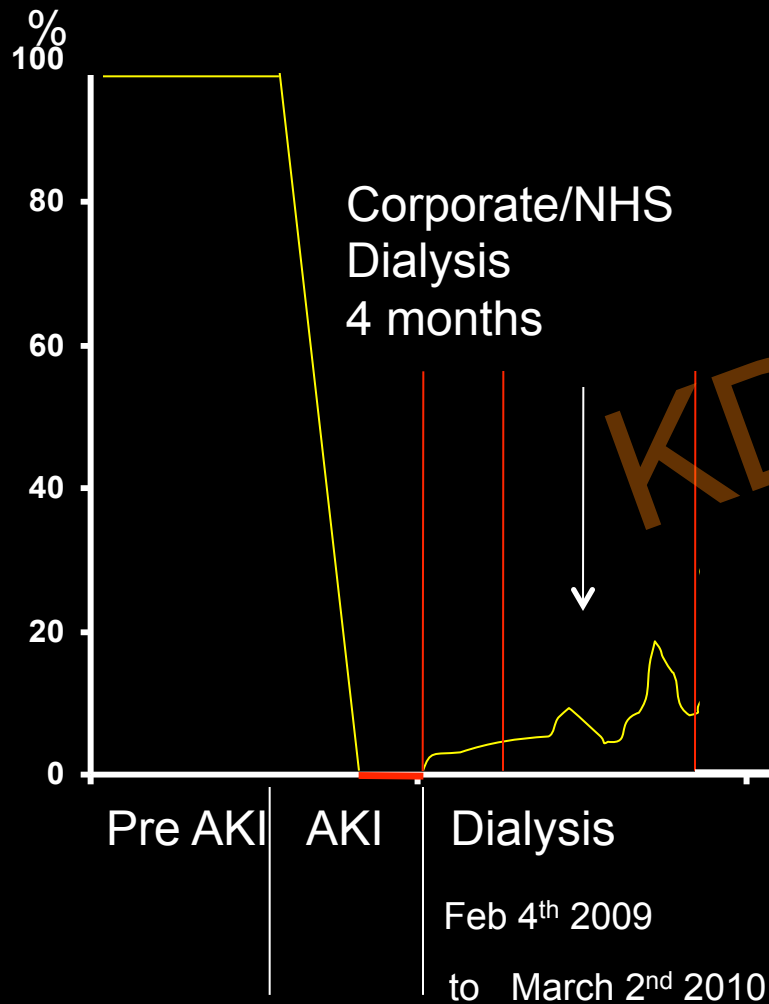
Subjective feeling of wellness



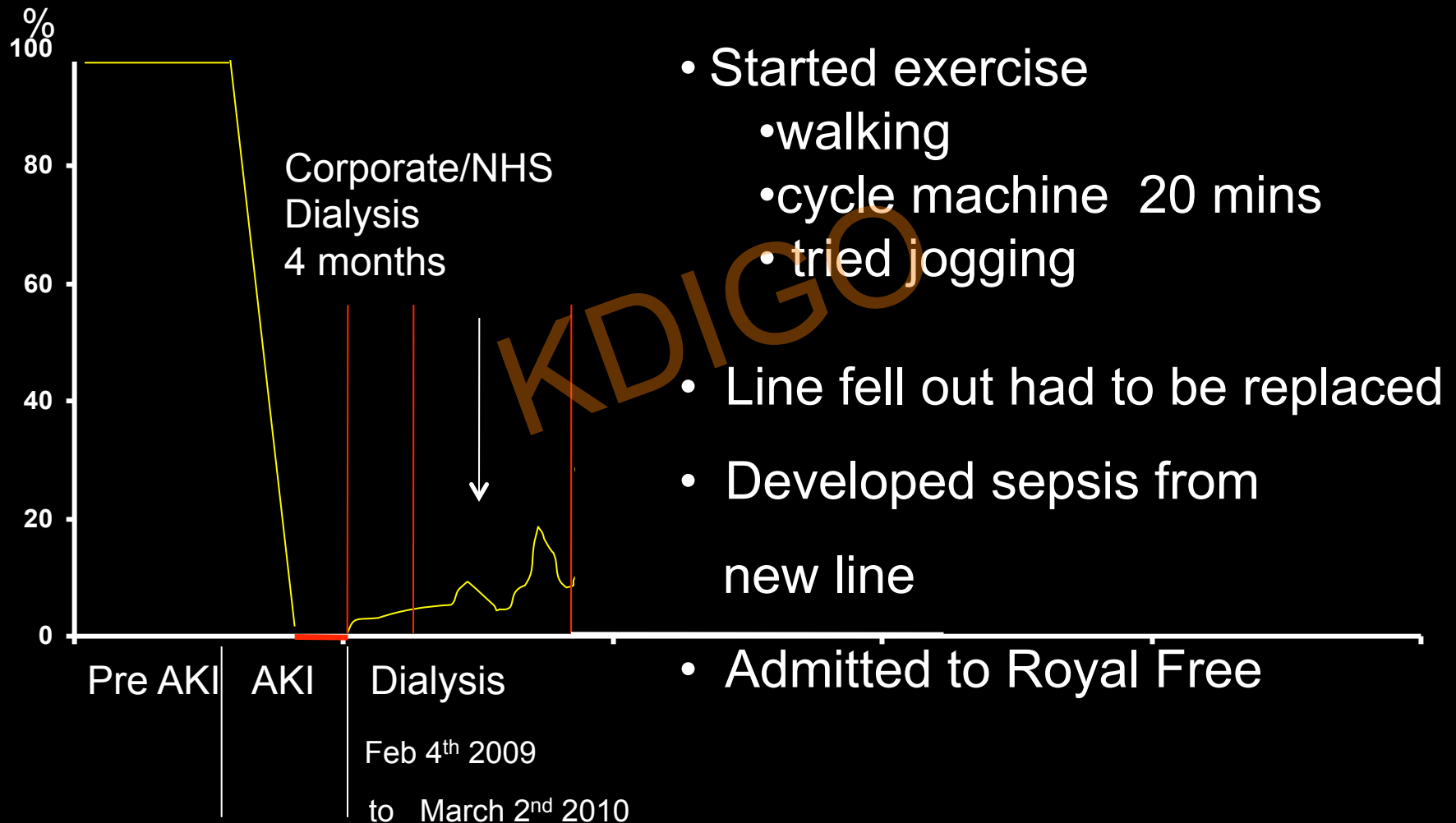
Subjective feeling of wellness

• DURING DIALYSIS

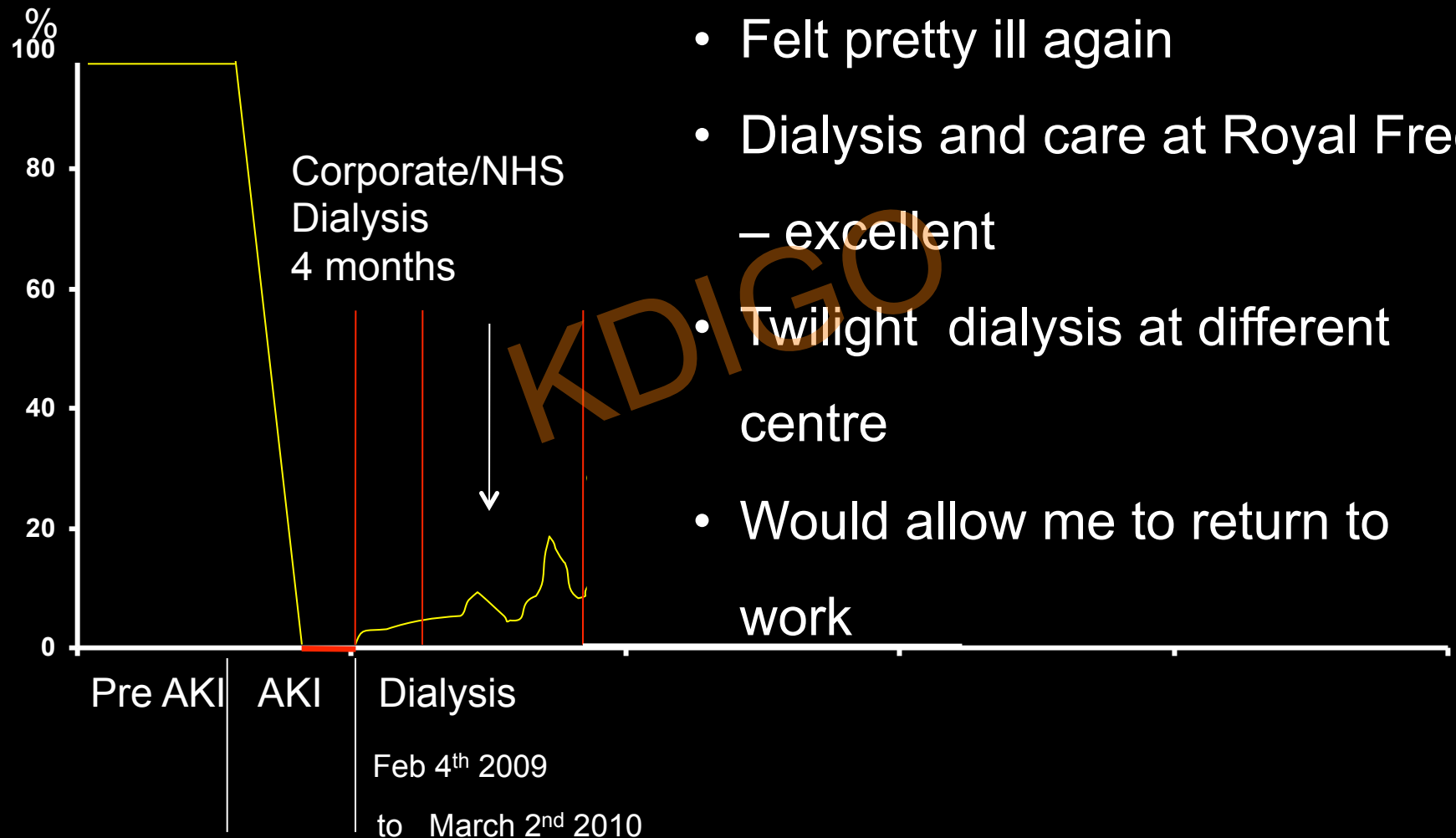
- Very nauseous and sleepy
- Little energy
- Very cold
- Cramps
- Hypotensive
- Large unit
- Sometimes short staffed so no time
- No manager
- Racial abuse



Subjective feeling of wellness



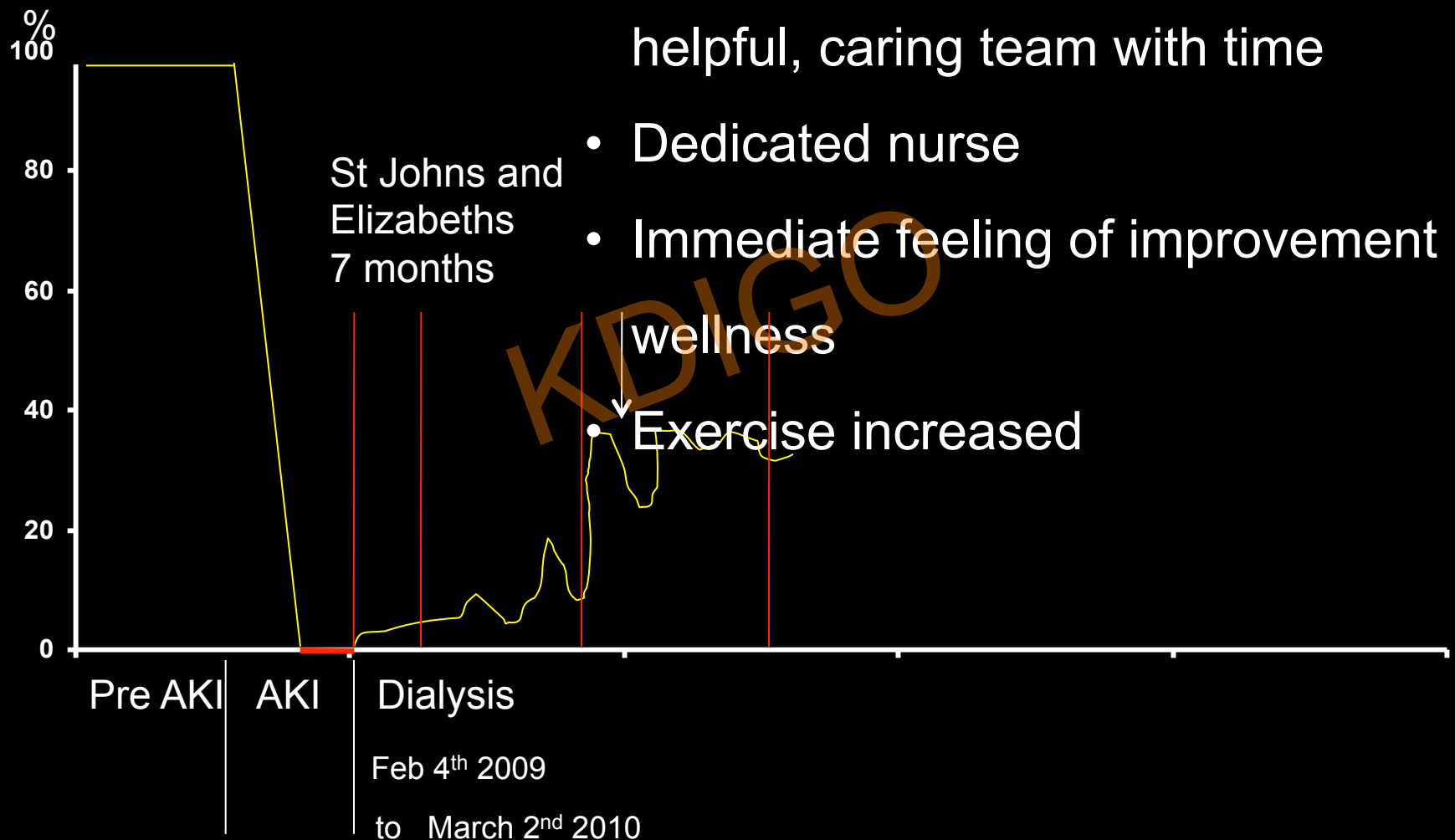
Subjective feeling of wellness



- Line removed for 1 week
- Felt pretty ill again
- Dialysis and care at Royal Free
 - excellent
- Twilight dialysis at different centre
- Would allow me to return to work

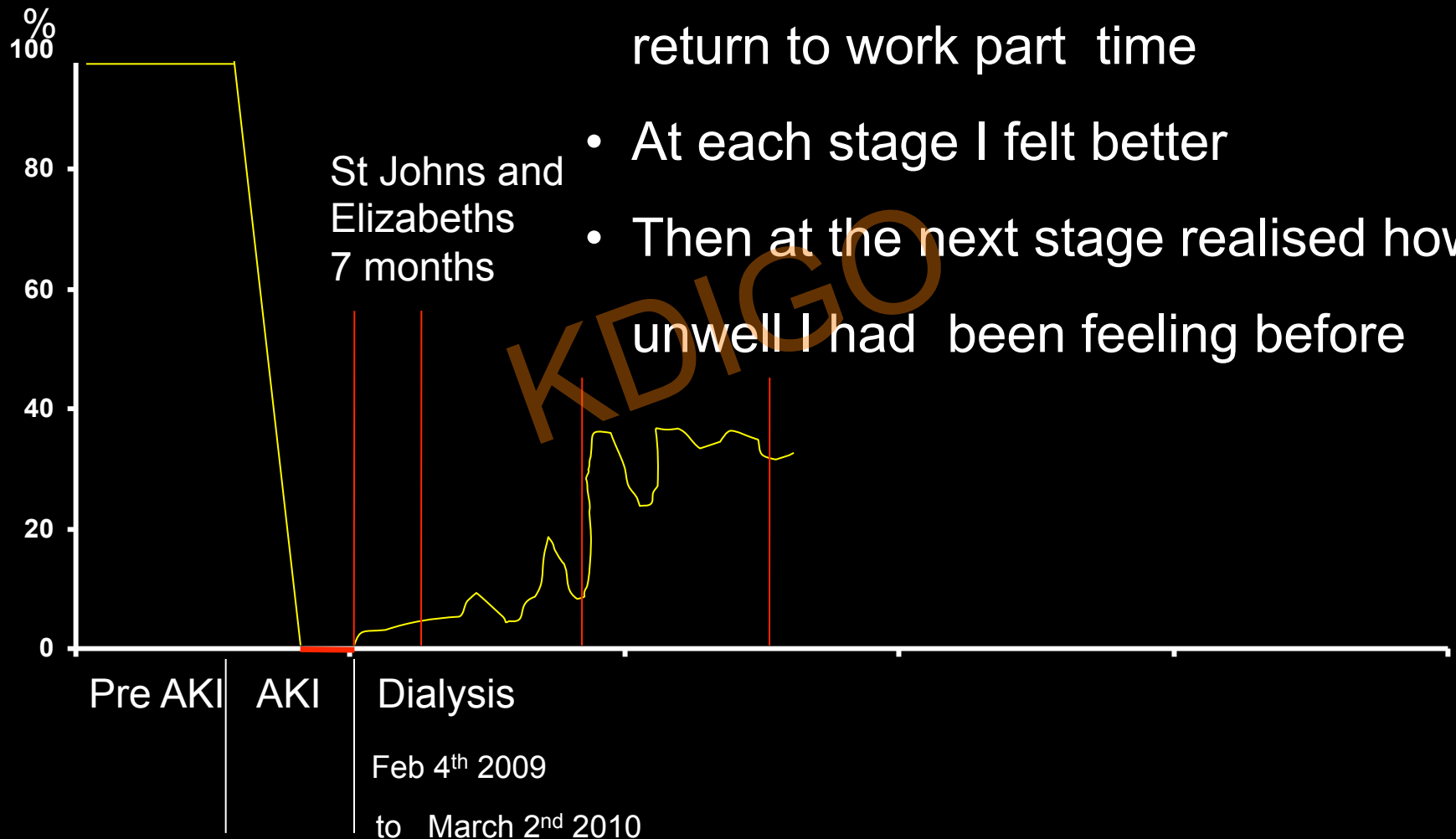
Subjective feeling of wellness

- Well managed very positive, calm, helpful, caring team with time
- Dedicated nurse
- Immediate feeling of improvement in wellness
- Exercise increased



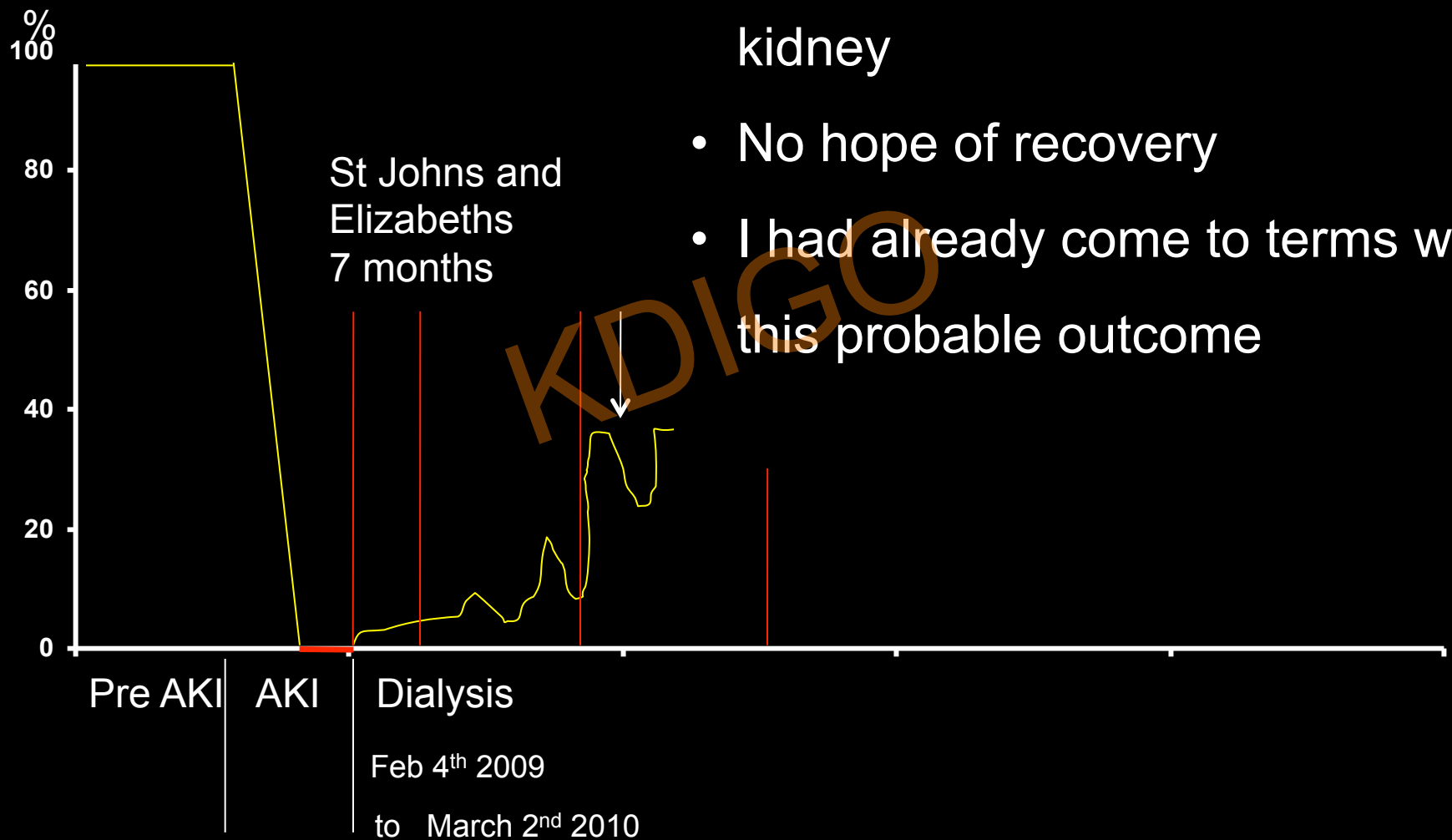
Subjective feeling of wellness

- Evening dialysis enabled me to return to work part time
- At each stage I felt better
- Then at the next stage realised how unwell I had been feeling before



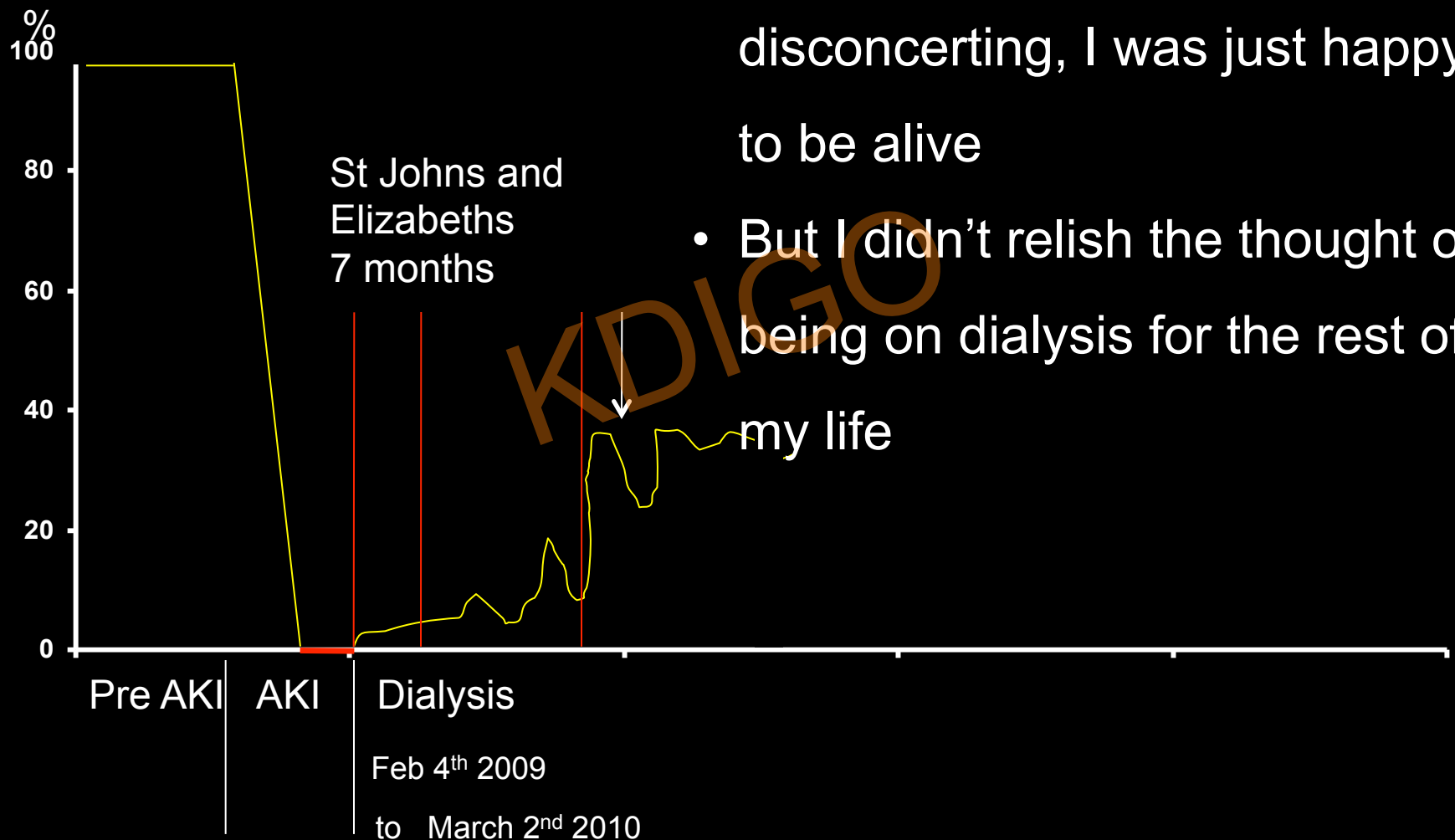
Subjective feeling of wellness

- Biopsy result severe fibrosis of kidney
- No hope of recovery
- I had already come to terms with this probable outcome



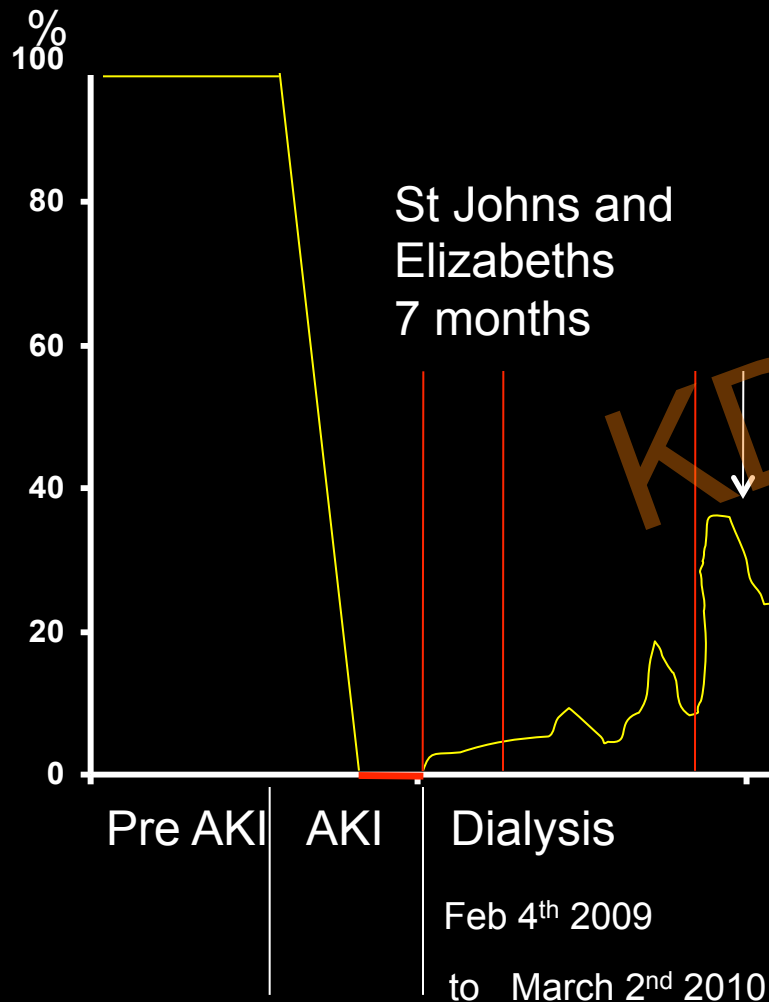
Subjective feeling of wellness

- I truly did not find the result disconcerting, I was just happy to be alive
- But I didn't relish the thought of being on dialysis for the rest of my life



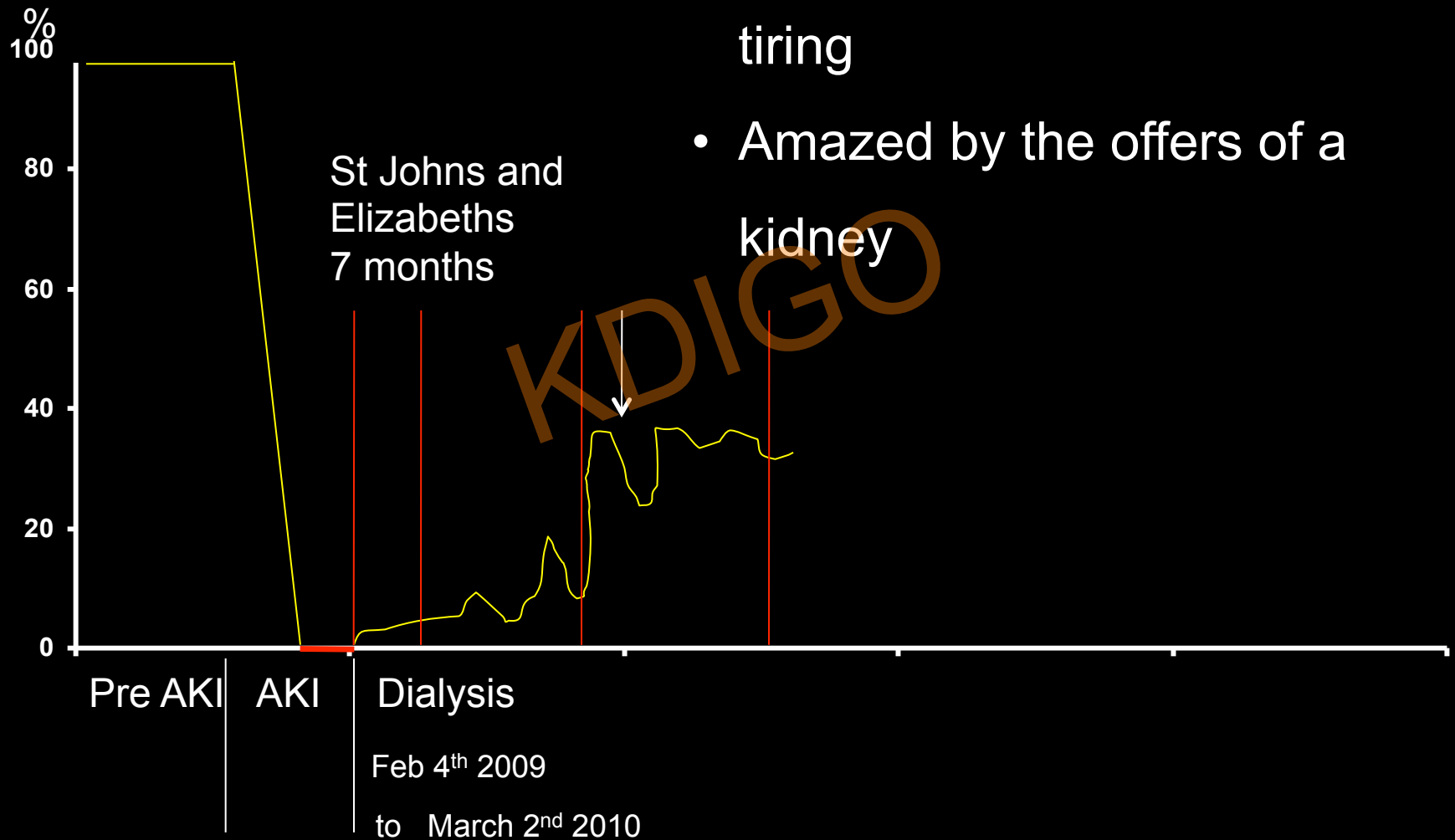
Subjective feeling of wellness

- Whilst I appreciated that it kept me alive I felt a bit like a prisoner trapped for so long by a machine 3 days/week
- Met patients who thought dialysis was a curative treatment
- On transplant waiting list which felt positive

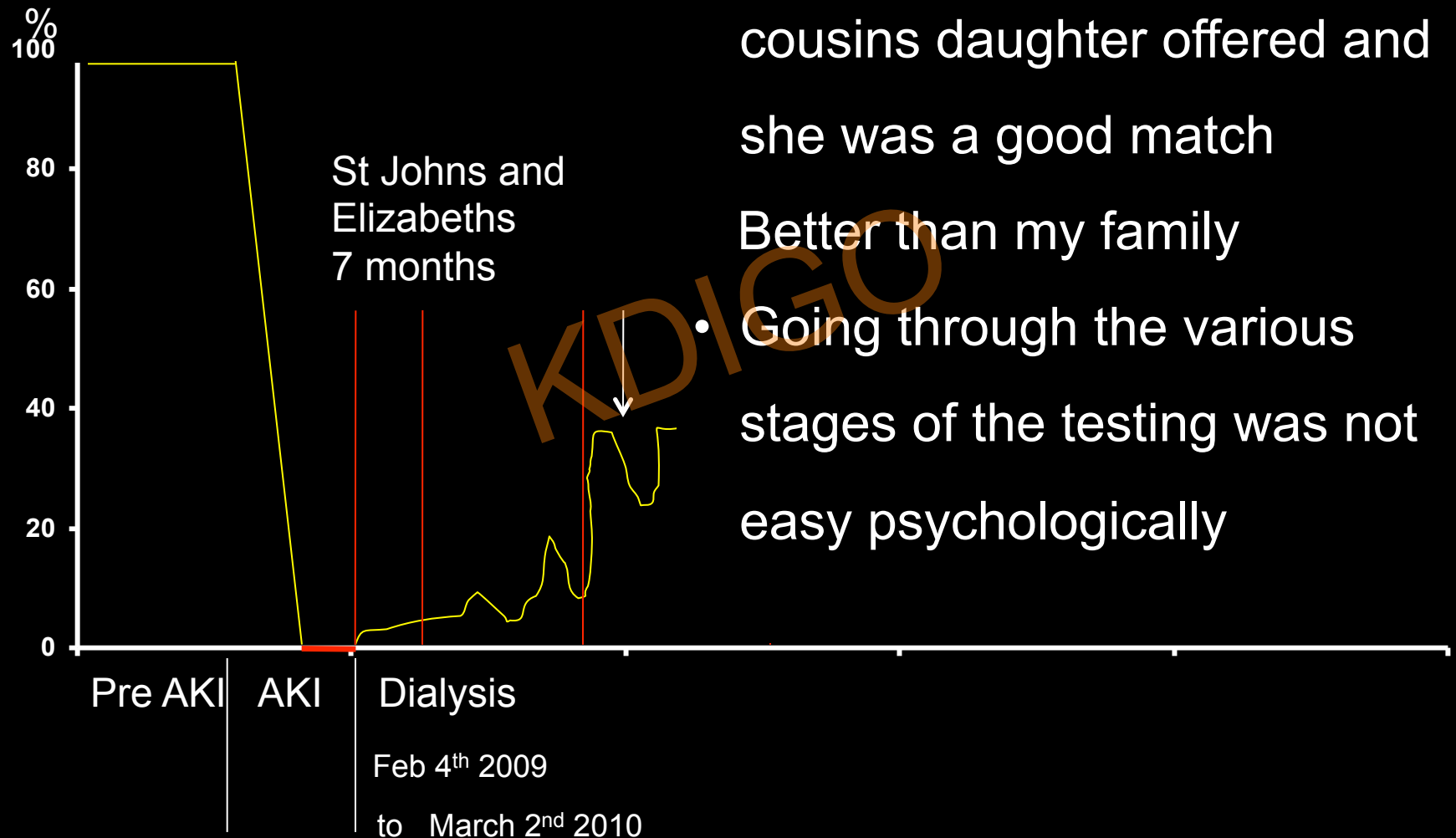


Subjective feeling of wellness

- Managed to work well but very tiring
- Amazed by the offers of a kidney



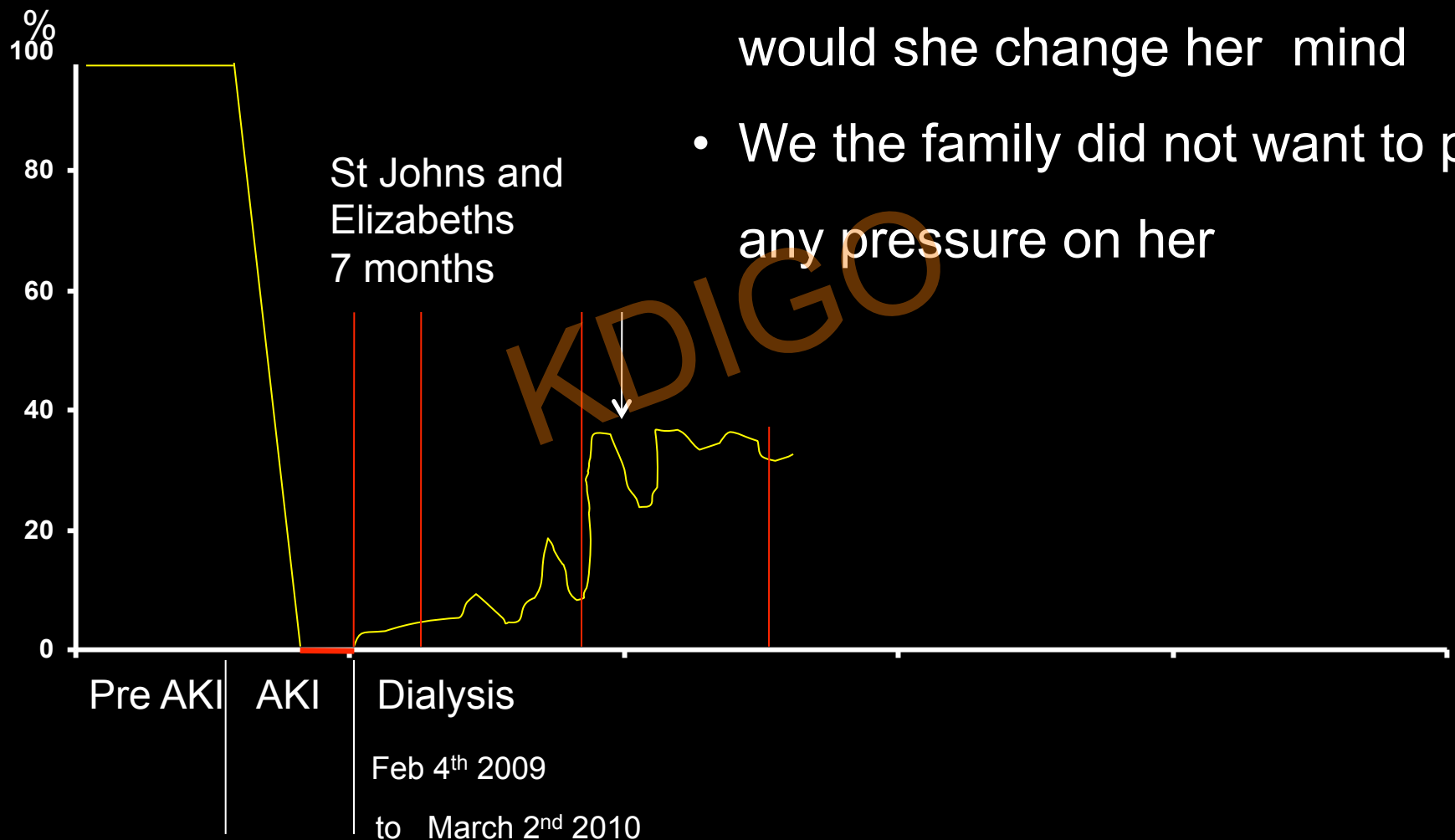
Subjective feeling of wellness



- Then out of the blue my wife's cousins daughter offered and she was a good match
- Better than my family
- Going through the various stages of the testing was not easy psychologically

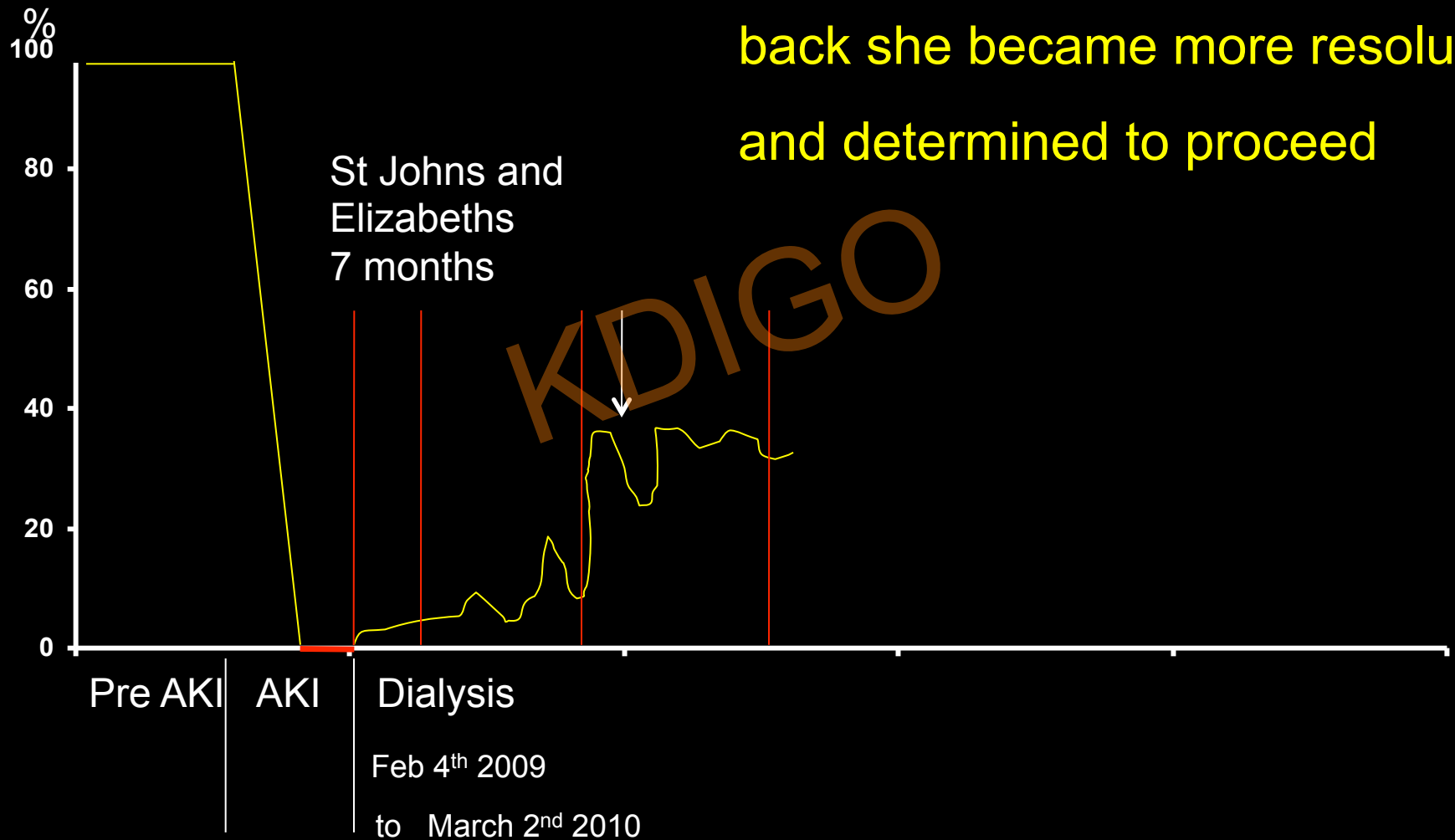
Subjective feeling of wellness

- Not just would she “pass” but would she change her mind
- We the family did not want to put any pressure on her



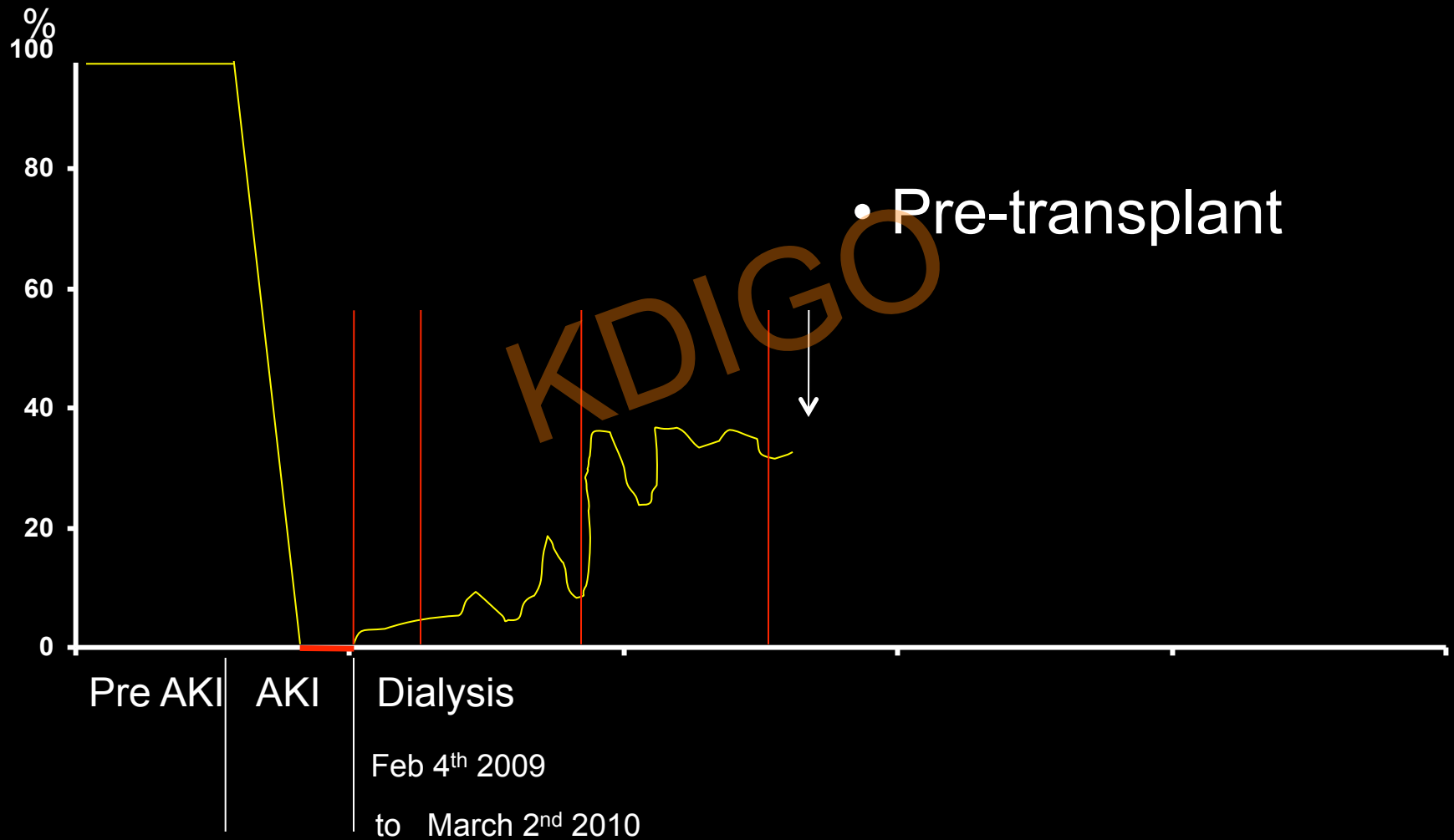
Subjective feeling of wellness

- Amazingly as each test came back she became more resolute and determined to proceed



- How do you say thank you to someone who is offering to give your life back to you?
- Nothing you can say or do is enough
- I resolved to tell her that and explain how I felt

Subjective feeling of wellness



- Information from surgeon
- Group meeting at Royal Free
- Information directly from patient
- Transplant team very supportive
- Echocardiogram
- No symptoms
- Some left ventricular damage
- Angiogram – left descending coronary 85% occluded
- Diagonal completely occluded
- Stent

Subjective feeling of wellness

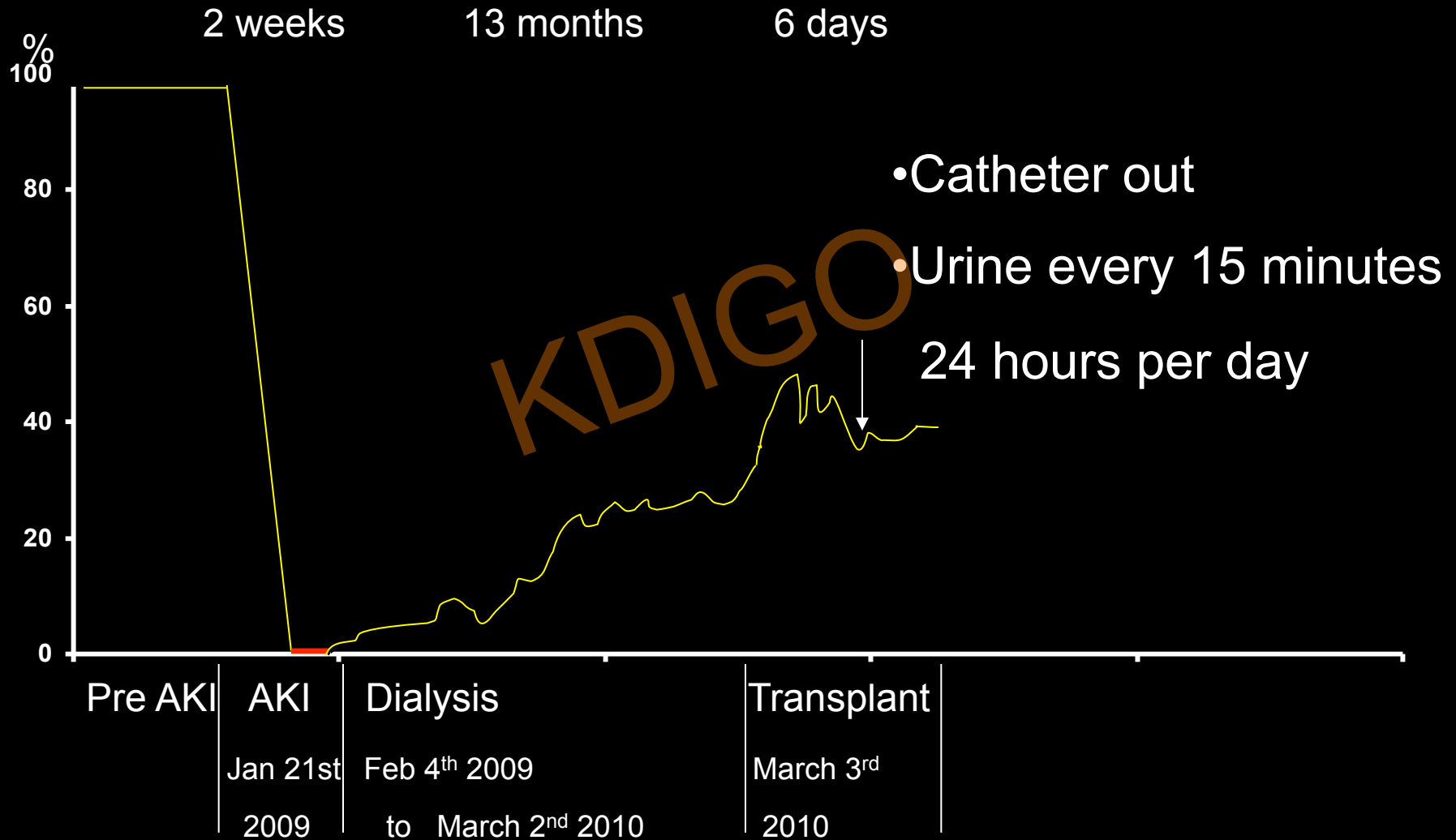


Subjective feeling of wellness



- Woke up
- Great to be alive
- No nausea – amazing
- Self administered pain relief - no pain
- Up next day walking
- Tramadol – completely controlled pain
- Nursing excellent
- Drink > 3 litres/day compared to max of 1 litre

Subjective feeling of wellness



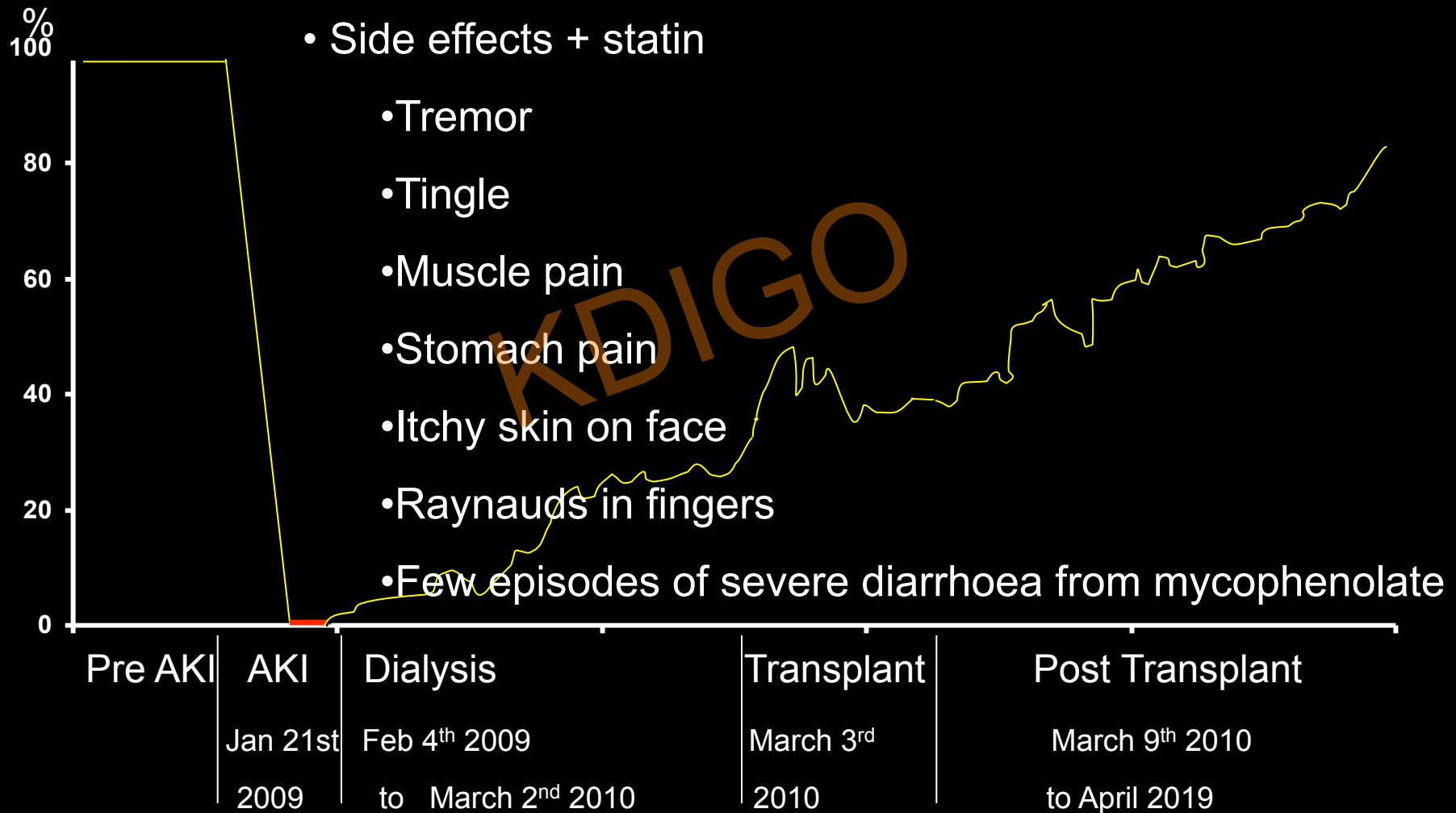
Subjective feeling of wellness



Subjective feeling of wellness

9 Years post transplant

- Gradual improvement – urine stable 2 weeks
- Side effects + statin



• Tremor

• Tingle

• Muscle pain

• Stomach pain

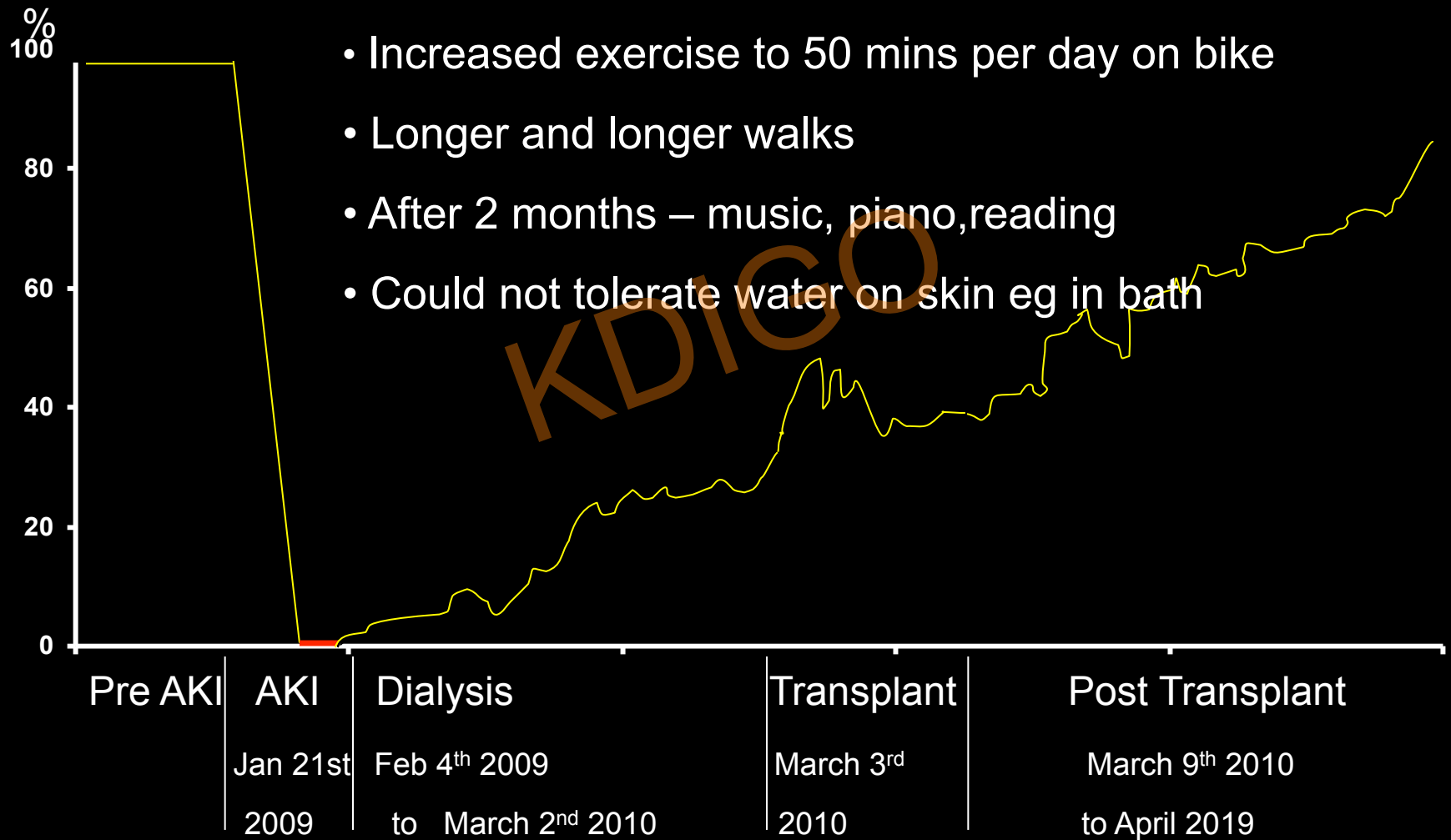
• Itchy skin on face

• Raynauds in fingers

• Few episodes of severe diarrhoea from mycophenolate

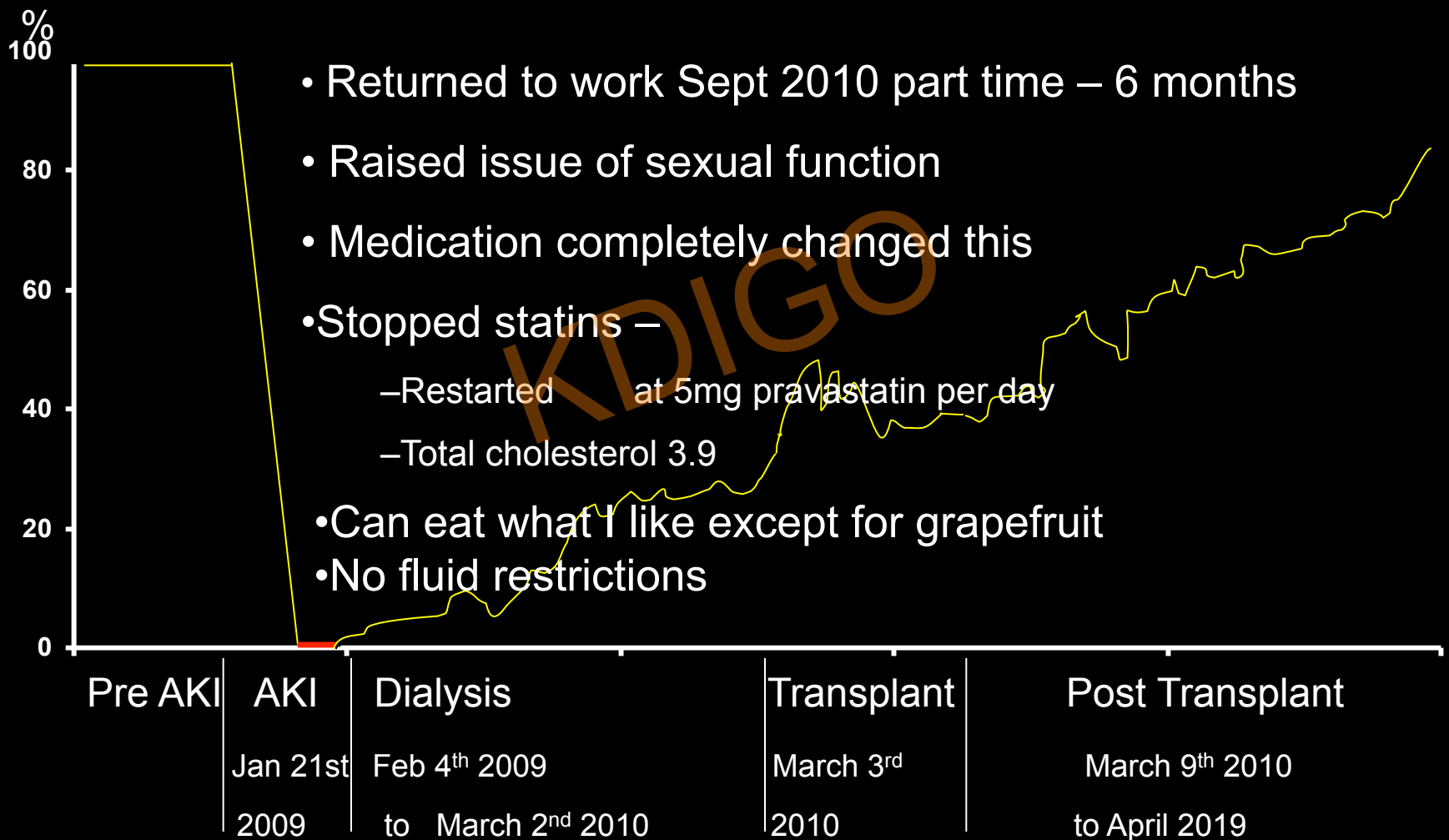
Subjective feeling of wellness

9 Years post transplant



Subjective feeling of wellness

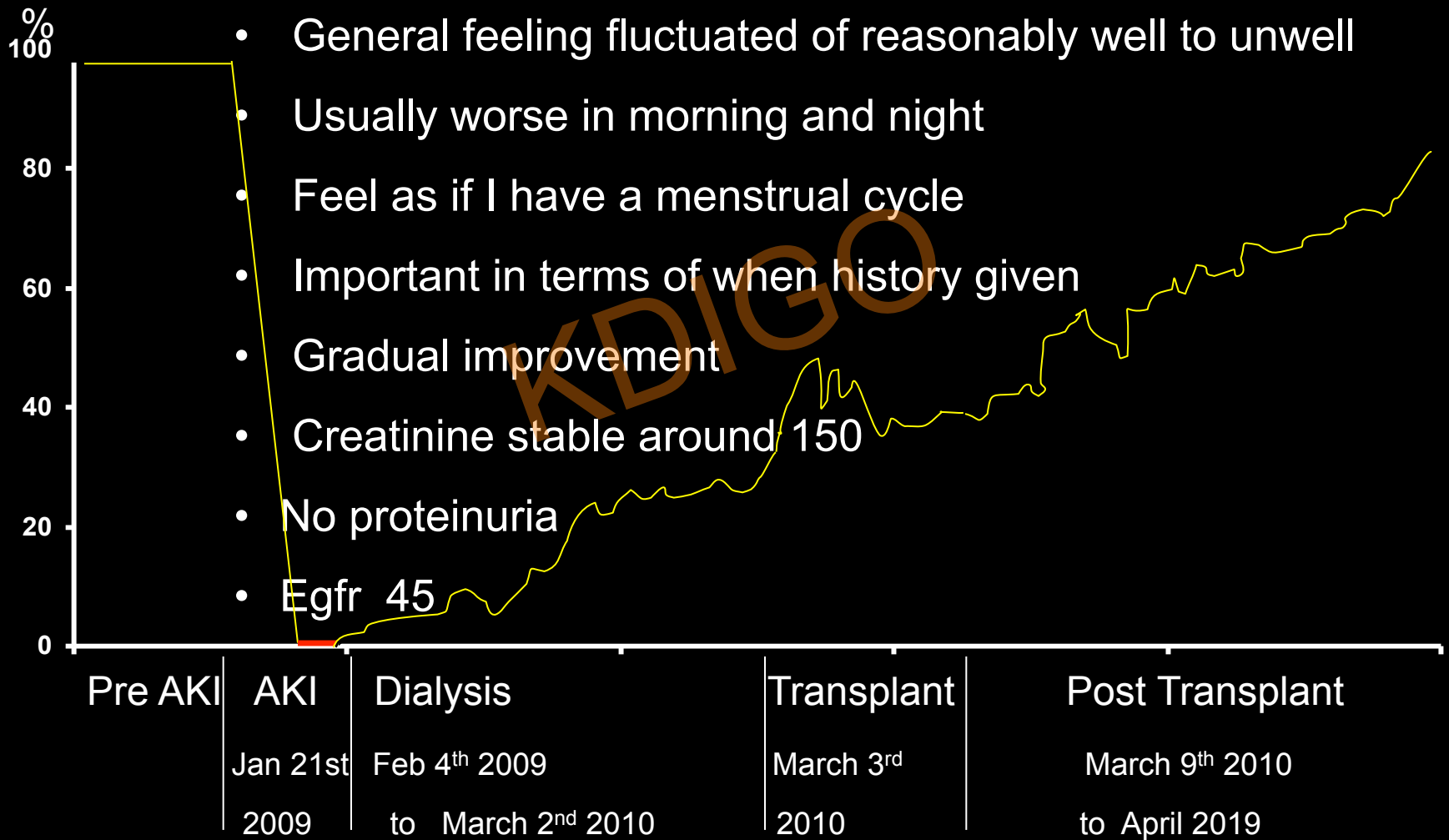
9 Years post transplant



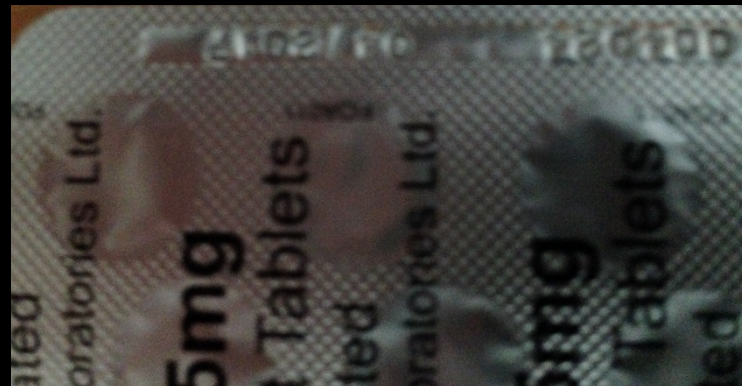
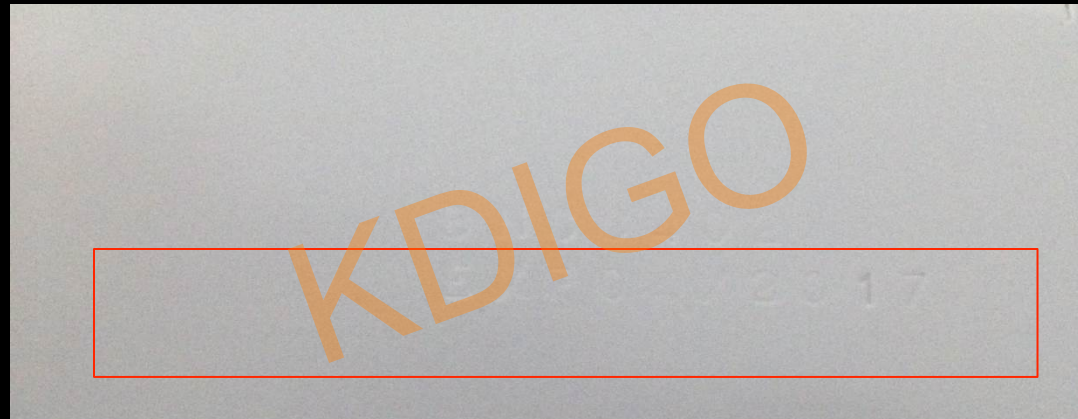
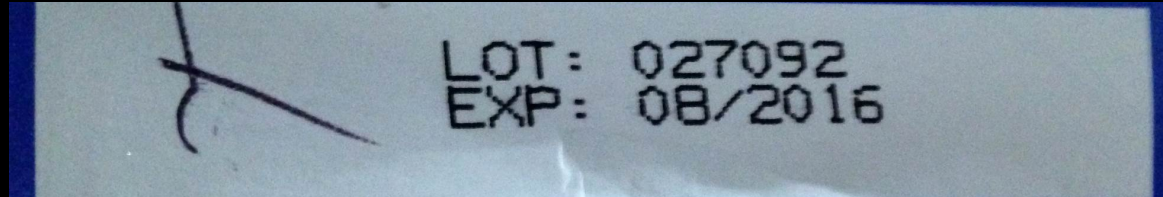
Subjective feeling of wellness

9 Years post transplant

- Started tennis – interesting with no toes
- General feeling fluctuated of reasonably well to unwell
- Usually worse in morning and night
- Feel as if I have a menstrual cycle
- Important in terms of when history given
- Gradual improvement
- Creatinine stable around 150
- No proteinuria
- Egfr 45



24 pills/capsules a day
Clear packaging makes a big difference



What has effect been

- It has reinforced my views of what is important in life
- I smile when I hear people getting angry, frustrated, intolerant about things that really don't matter
- I try and avoid things that make me unhappy
- I live more in the moment
- I do not worry about things that may never happen
- I marvel every day at the gift that my donor has given to me and my family

What has effect been

- I would like to help more people
- My relationships with my immediate family and close friends are stronger, more meaningful and fulfilling
- I retired from clinical practice to teach, mentor and have time
- I am amazed by the quality of care that I have and am receiving from the NHS

Dialysis and post transplant/fluids

- Guides on controlling fluid intake poor
- Easy to become dehydrated or overloaded
- But how hydrated do you need to be?
- Is urine colour really a good sign?
- Wearables would be a great help particularly in:
 - Heat
 - Exercise
 - Illness temperature +/- vomiting and diarrhoea

Patient confusion over term nephrotoxin

- Whether drugs damage the kidney directly
- Or do they act indirectly
- The term is confusing and scary

KDIGO

Patient confusion over term nephrotoxin

- The kidney is very precious
- Patient may over-interpret advice and stop drug treatment during minor illness
- Patient may panic at term nephrotoxic and consider potential harm outweighs potential benefit
- May stop taking drug permanently
- May not return to correct level when re-starting

Subjective feeling of wellness



Subjective feeling of wellness



2011



2016



February 2019
8 miles per day
for 6 days in the
desert



I have been given me back not only my life

But also

My ability to live my life

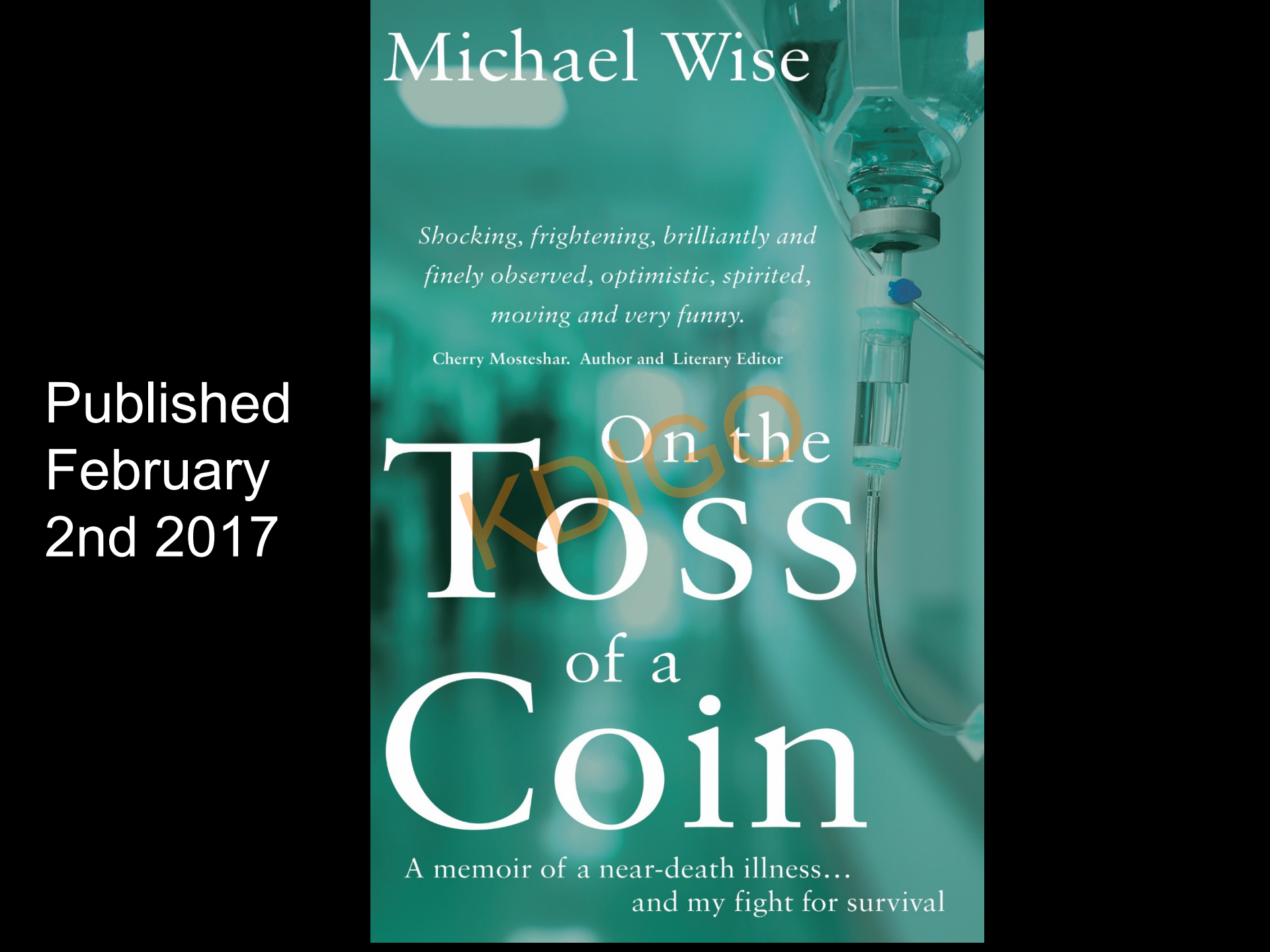
KDIGO

Lets hope you can improve the patient's
experience of the journey from



to



The background of the entire image is a teal color. On the right side, there is a vertical image of an IV drip chamber with a clear plastic tube and a blue stopper. The drip chamber is filled with a clear liquid, and a small amount of liquid is visible in the chamber. The tube extends downwards from the chamber.

Michael Wise

*Shocking, frightening, brilliantly and
finely observed, optimistic, spirited,
moving and very funny.*

Cherry Mostesha. Author and Literary Editor

On the
Toss
of a
Coin

A memoir of a near-death illness...
and my fight for survival

Published
February
2nd 2017