PERSPECTIVES FROM AN AKI SURVIVOR

Michael Wise
Age 72
AKI III aged 62
January 2009
Subjective feeling of wellness

- Specialist in Restorative Dentistry and Oral Surgery
- Visiting Professor Eastman Dental Institute, UCL
- Jogging 6 miles 3/week
- Singles tennis 1/week, mixed doubles twice
- Felt extremely well
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

- Suddenly to hospital
- Unconscious on arrival
- To resus unit then intensive care
- Rash developing on my chest
- Haemolytic Strep group A sepsis to toxic shock
- Multi-organ failure – including kidneys
Subjective feeling of wellness

- Medically induced coma
- Intubated

Pre AKI   AKI     Dialysis                       Transplant          Post Transplant

Jan 21st    Feb 4th 2009                          March 3rd                     March 9th 2010

2009         to   March 2nd 2010              2010                            to March 8th 2012

KDIGO
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”

Pre AKI | AKI | Transplant
Jan 21st 2009 to March 2nd 2010 | 2 weeks | 2009
March 3rd 2010 to March 8th 2012 | 2009

KDIGO
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

The London Clinic
7 weeks

KDIGO
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

Pre AKI | AKI | Dialysis | Post Transplant
Feb 4th 2009 to March 2nd 2010

The London Clinic 7 weeks

KDIGO
Subjective feeling of wellness

- **First 3 weeks**
  - Couldn’t:
    - walk
    - hold a spoon or shave
    - brush my teeth
    - write my name

The London Clinic
7 weeks

Pre AKI | AKI | Dialysis
Feb 4th 2009 to March 2nd 2010
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

- Cardiologist – echocardiogram/phone call

The London Clinic
7 weeks

Pre AKI | AKI | Dialysis
Feb 4th 2009 to March 2nd 2010

0% 100%

KDIGO
Subjective feeling of wellness

- First 3 weeks
  - We celebrated our 40\textsuperscript{th} 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

The London Clinic
7 weeks

- First 3 weeks
- We celebrated our 40\textsuperscript{th} 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 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

The London Clinic
7 weeks

KDIGO
I knew what kidneys do (50% don’t)

BUT

I didn’t know what happens when they don’t function
Felt extremely unwell and weak
Nauseous
Sleepy
Itching
Difficult to concentrate
Muscle cramps in legs at night
Lost libido
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

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The London Clinic
7 weeks

Corporate/NHS Dialysis
4 months
Subjective feeling of wellness

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

Pre AKI  | AKI | Dialysis | Post Transplant
Feb 4th 2009 to March 2nd 2010
Subjective feeling of wellness

- Dialysis pm 4.5 hours
- 3 days/week
- Dietary and fluid restrictions difficult

Pre AKI | AKI | Dialysis
Feb 4th 2009 to March 2nd 2010

Corporate/NHS Dialysis 4 months

KDIGO
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

Pre AKI | AKI | Dialysis
--- | --- | ---
Feb 4th 2009 to March 2nd 2010

Corporate/NHS Dialysis 4 months

KDIGO
Subjective feeling of wellness

- Started exercise
  - walking
  - cycle machine 20 mins
  - tried jogging
- Line fell out had to be replaced
- Developed sepsis from new line
- Admitted to Royal Free

Pre AKI | AKI | Dialysis
Feb 4th 2009 to March 2nd 2010

Corporate/NHS Dialysis 4 months

KDIGO
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

Pre AKI | AKI | Dialysis
Feb 4th 2009 to March 2nd 2010

St Johns and Elizabeths 7 months
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

Pre AKI | AKI | Dialysis
Feb 4th 2009 to March 2nd 2010

St Johns and Elizabeths 7 months
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

KDIGO

Pre AKI | AKI | Dialysis
Feb 4th 2009 to March 2nd 2010

St Johns and Elizabeths 7 months
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

St Johns and Elizabeths 7 months

Pre AKI  |  AKI  |  Dialysis
Feb 4th 2009 to March 2nd 2010

KDIGO
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

Pre AKI | AKI | Dialysis | Post Transplant
---|---|---|---
Feb 4th 2009 to March 2nd 2010
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

KDIGO
Subjective feeling of wellness

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

St Johns and Elizabeths
7 months

The London Clinic
7 weeks

The graph shows the subjective feeling of wellness over time:
- Pre AKI
- AKI
- Dialysis
- Post Transplant

Timeline:
- Feb 4th 2009 to March 2nd 2010
• 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

Pre AKI   AKI     Dialysis                       Transplant          Post Transplant
Feb 4th 2009 to March 2nd 2010

KDIGO
• 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
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**Subjective feeling of wellness**

- 2 weeks
- 13 months
- 6 days

KDIGO
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

- Catheter out
- Urine every 15 minutes
- 24 hours per day

Pre AKI  AKI  Dialysis  Transplant  Post Transplant

Jan 21st  Feb 4th 2009  March 3rd  March 9th 2010
2009 to March 2nd 2010  2010 to March 8th 2012

2 weeks  13 months  6 days
Subjective feeling of wellness

- Pre AKI: Jan 21st, 2009
- AKI: Feb 4th, 2009 to March 2nd, 2010
- Dialysis: March 3rd, 2010 to April 2019
- Transplant: March 3rd, 2010
- Post Transplant: 9 years post transplant

KDIGO
Subjective feeling of wellness

- 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

Pre AKI: Jan 21st 2009
AKI: Feb 4th 2009 to March 2nd 2010
Dialysis: March 3rd 2010
Transplant: March 9th 2010 to April 2019

9 Years post transplant
Subjective feeling of wellness

9 Years post transplant

- Increased exercise to 50 mins per day on bike
- Longer and longer walks
- After 2 months – music, piano, reading
- Could not tolerate water on skin eg in bath
Subjective feeling of wellness

9 Years post transplant

- Returned to work Sept 2010 part time – 6 months
- Raised issue of sexual function
- Medication completely changed this
- Stopped statins –
  - Restarted at 5mg pravastatin per day
  - Total cholesterol 3.9
- Can eat what I like except for grapefruit
- No fluid restrictions

Pre AKI
- Jan 21st 2009

AKI
- Feb 4th 2009

Dialysis
- Feb 4th 2009 to March 2nd 2010

Transplant
- March 3rd 2010

Post Transplant
- March 9th 2010 to April 2019
Subjective feeling of wellness

- 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

9 Years post transplant

Pre AKI | AKI | Dialysis | Transplant | Post Transplant

KDIGO
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
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

- Feel pretty well
- Heart revascularised
- Love life and take pleasure in every day
- Love my family
- Renewed sexual relationship with my wife

KDIGO
Subjective feeling of wellness

- Ski, tennis, walk
- Enjoy music, theatre, reading
- Grateful to be alive
- Can participate professionally
- Non restrictive diet except for grapefruit

Pre AKI: Jan 21st 2009
AKI: Feb 4th 2009 to March 2nd 2010
Dialysis: March 3rd 2010
Transplant: March 9th 2010 to April 2019
Post Transplant: 9 Years post transplant

KDIGO
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
Let's hope you can improve the patient's experience of the journey from
On the Toss of a Coin

Michael Wise

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

Published February 2nd 2017