The importance of patient education and motivation in the management of mineral bone disorder – a 360° approach

Corporate Education Session (CES)
at EDTNA/ERCA 2017

Moderator: Isabel Walker

Sponsored by

VIFOR FRESENIUS MEDICAL CARE
RENAL PHARMA

CHZH/VEL/17/0249d

Welcome and introduction: opening the circle

Isabel Walker
UK

Disclosures

Isabel Walker
- No disclosures

Daniel Gallego
- No disclosures

Helga Frank
- Amgen
- HEXAL
- MSD Sharp & Dohme GmbH
- Novartis Pharma
- Sanofi
- Vifor Fresenius Medical Care Renal Pharma

Stefaan Claus
- Vifor Fresenius: sponsor of this meeting
- Bellco: advisor in development of the CARPEDIEM™

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- The faculty are responsible for the content of the programme
- The views expressed are those of the faculty and not necessarily those of Vifor Fresenius Medical Care Renal Pharma

Housekeeping

- Please switch off/mute your mobile phone

Programme

14.00	**Welcome and introduction: opening the circle** *Isabel Walker, UK*
14.05	**The burden of renal disease: the patient's perspective** *Daniel Gallego, Spain*
14.20	**Why it matters to control hyperphosphataemia: the nephrologist's view** *Helga Frank, Germany*
14.35	**Patient education and motivation: the role of the renal nurse** *Stefaan Claus, Belgium*
14.50	**Panel discussion** *Isabel Walker, UK; All*
15.10	**Closing the circle** *Isabel Walker, UK*

Question cards

- Please write your questions on the cards provided and give them to the support staff

The burden of renal disease: the patient's perspective

Daniel Gallego
Spain

KRAKOW, 10 SEPTEMBER 2017
True Partnership and Global Approach
in Management of Renal Care

The Burden of Renal Disease: Patient Perspective

Daniel Gallego

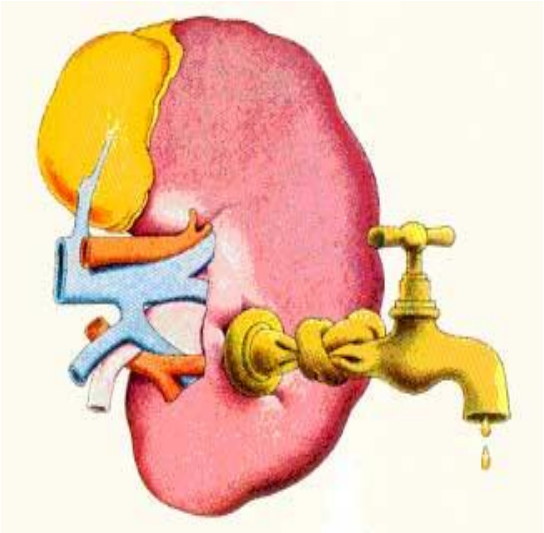
CHZH/VEL/17/0249c

Disclosures

- No disclosures to make

A Bit About Me…

- Kidney disease August 1993
- First haemodialysis (HD) May 1995
- Denial, anger, depression
- Acceptance
- Born again, FULL RESET, new life
- Always HD in a centre, never peritoneal dialysis (PD) or home HD
- Self-caring and active lifestyle
- RENAL PERSON



Active Life and Voyager

- I depend on a machine to survive
- The machine is available worldwide
- Basketball team
- Just do it
- I LOVE HD, I don´t hate it
- Impossible is nothing
- Renal voyager around the world
- WE CAN LIVE WITHOUT PEEING!!

Meaning of CKD

- Identity crisis
- Rejection of appearance
- Aversion to dialysis and medication
- Limiting lifestyle
- Fear and uncertainty
- What it means to be ‘normal’
- 70% of patients diagnosed with CKD believe they are going to die of this condition[1]

CKD, chronic kidney disease

1. Strippoli GF. Collaborative Depression and Sexual Dysfunction (CDS) in Hemodialysis Working Group

The 4 F Instincts

FOOD & FLUID

FIGHT

FLEE

FUCK

✓ STIMULATE REWARD in mammals to be HAPPY

Food is a Pleasure

- Where is the BALANCE between enjoying life (meals, trips, parties) and ADHERING TO TREATMENT?
- Our society celebrates everything by…

  Eating and drinking (EATING IS A REAL PLEASURE)

  – Learn to say "NO", **The Spoon with Holes**

  – Meals abroad, most dieters are depressed without CKD

- **We are what we eat, and we are what we leave behind**

What Patients Need To Know…

- Dialysis sessions DON´T REMOVE ENOUGH PHOSPHORUS
- Phosphorus is present in EVERY MEAL

  Especially **processed food** or **'junk' food**

  Patients don't understand the **protein-phosphorus ratio**
- **Consequences of** ↑ PHOSPHORUS:

  Less **quality of life**

  Mineral bone disorder

  Rapid **atherosclerotic process**

  High parathyroid hormone (**PTH**)

  Painful joints

  Itchiness

Explanations: Easy And Simple

✓ LABELS

Phosphorus is not required to be listed on the nutrition label

- If it is not listed, it does not mean that it is not in the food
- You can see 'hidden' sources of phosphorus in your meals
- If you can't understand what you read in a label don't eat it!

✓ REMEMBER TO TAKE YOUR BINDERS

Always take your binders with your meals and snacks, as directed by your physician

Keep extra binders with you for meals and snacks eaten away from home

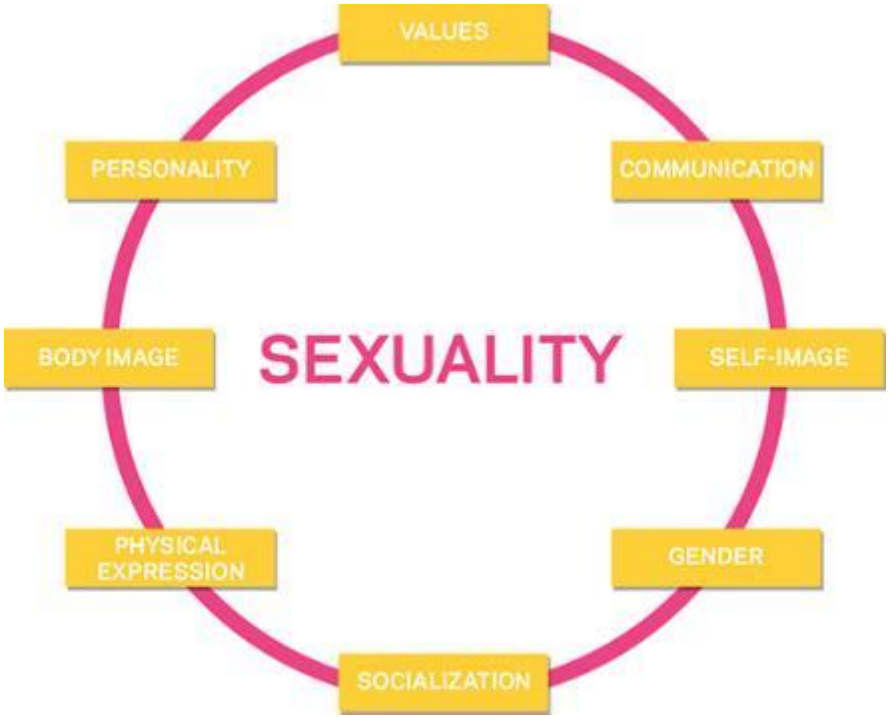
Ask your dietician or nurse for advice at any time regarding diet choices or medications

Thirst

- Patients with CKD are **THIRSTY 24/7**
- To walk through the desert saying **“NO”**…
- It becomes an **obsession (infinite thirst)**
- **Regret, guilt,** madness
- Counting **KILOS / LITRES**

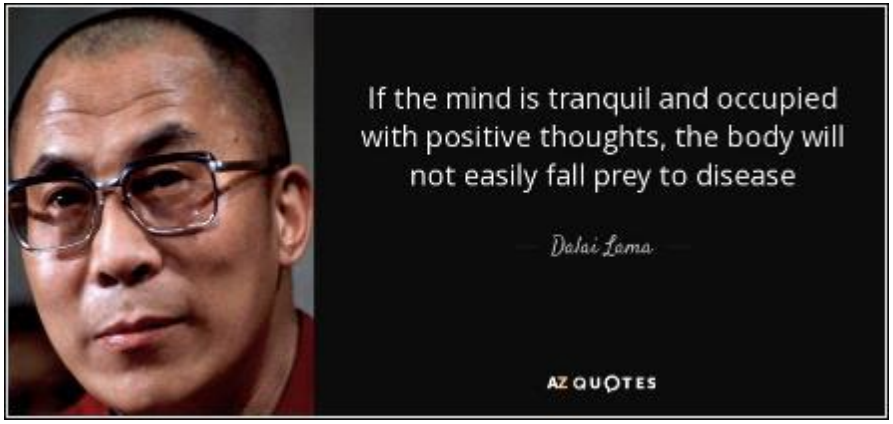
Sexuality in CKD

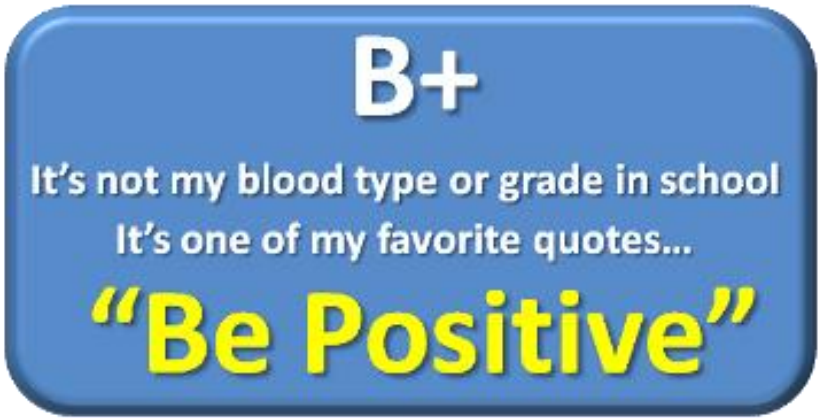
- First thought, 'I'm not going to have a partner'
- Broken toy
- Tell your 'secret'
- Sex with fistula catheter
- Sincerity ⇔ pleasure
- **Sex** is relative, don't compare



Positive Thinking

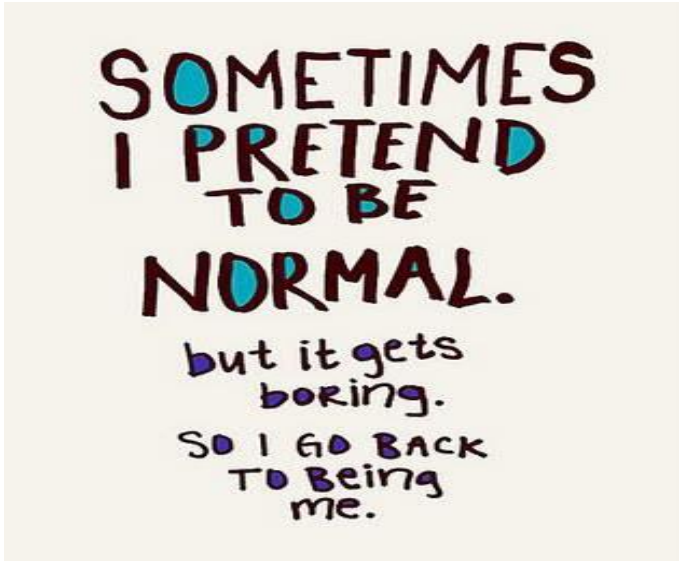
A. What we think determines what we will become
B. If I think I can't, I probably won't do it
C. Brain = SEE / IMAGINE / DREAM
D. No way as way, and no limitation as limitation





Accepted Suffering

- Attitude
- Maturity
- Overcoming
- Survival
- Enjoy life despite your health
- If you have a ‘WHY’,
  you will always find a ‘HOW’
  (Victor Frankl)



Two Kinds of Tourism

- Bookings, hotels, flights
- Luggage, airports, maps
- Hospitals and dialysis units
- Worried? Focus on things that I control

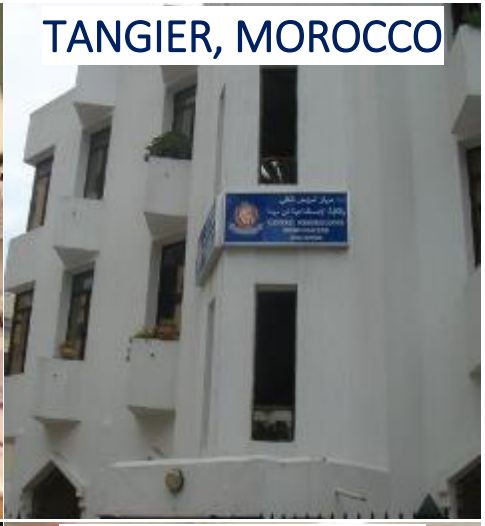
Live, Dream ❤ Travel





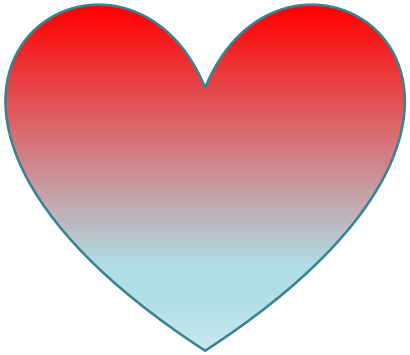



The Dialytic ♥ Trip



ACTIVE life

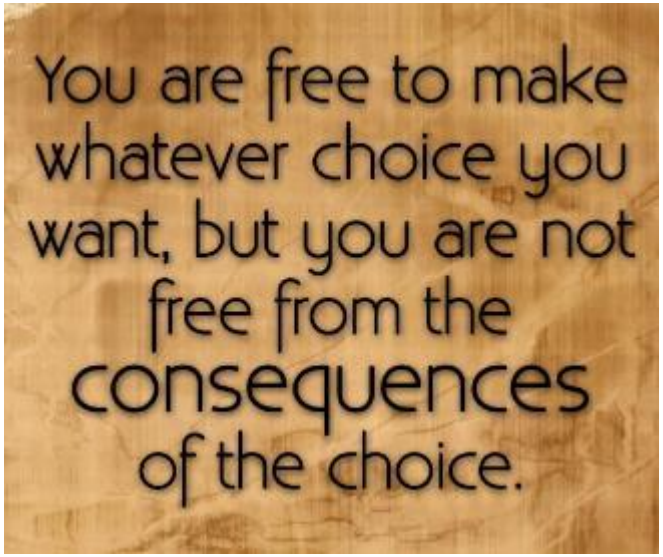
RENAL
PERSON



Patients: We are Adults

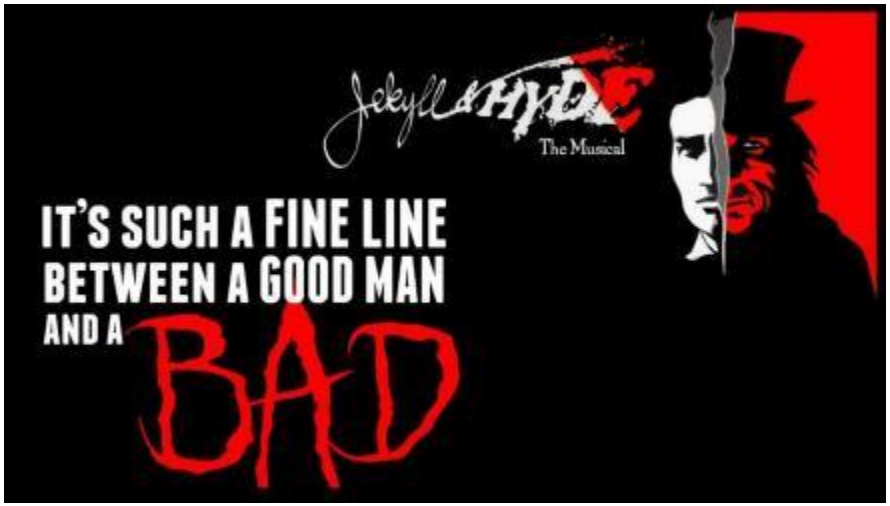
- ❑ Absolute, strict diet = failure
- ❑ It's my life, it's my responsibility
- ❑ Listen and involve us in the treatment

  Partnership to take decisions
- ❑ **NO DECISION ABOUT ME WITHOUT ME**



Psychological and Emotional Disorders

- ❑ Must be addressed in CKD
- ❑ Acceptance of the disease
- ❑ We need practical tools
- ❑ Ongoing assessment
- ❑ Involvement in the therapy
- ❑ Sleeplessness
- ❑ Good quality of life with CKD



Family / Caregivers

- They are extremely important in managing CKD
- **Help them to understand and be involved**
- They adapt their lifestyle, agenda, menus to CKD
- Programme education not only for patients
- Manage situations and aspects related to CKD

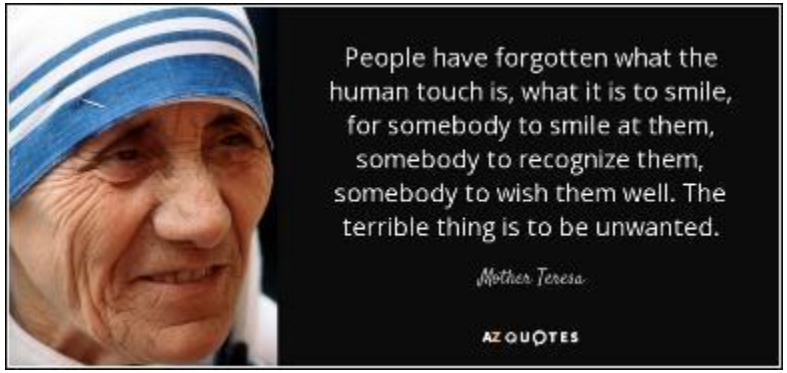
Family Caregiving

Promoting Physical Activity

1. Physical and mental (home-dialysis-home)
2. **Avoid overprotection!!**
3. Patients are adults, they require information and patience
4. Use the time of treatment wisely (exercise bike, healthcare messages, read…)
5. Promote physical activity (walk, cook, be active…)

What Makes a Difference to Me?

- ❑ The HUMAN TOUCH
- ❑ No decision about me, WITHOUT ME
- ❑ Involve patients IN SELF-CARING, ADHERENCE
- ❑ Ask US for strategies and renal programmes
- ❑ The MORE SIMPLY YOU EAT, The BETTER YOU´LL FEEL
- ❑ Work on ACCEPTANCE of the CKD
- ❑ Nutritionist, psychologist, social worker (staff dialysis units)



Acknowledgement

- By treating us, listen to us and understand us
- Model-based healthcare person
- Be reliable, our confidants
- Shared decisions = partnership

- GIVE YOUR BEST EVERY DAY

Muchas gracias
Thank you very much

EDTNA/ERCA

ALCER
Federación Nacional

DIALYSIS WITHOUT BORDERS
Building an Equitable World

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Why it matters to control hyperphosphataemia: the nephrologist's view

Helga Frank
Germany

Why it matters to control hyperphosphataemia: the nephrologist's view

EDTNA/ERCA 2017 in Krakow

Helga Frank
Nephrocare Starnberg
Germany

CHZH/VEL/17/0249a

Disclosures – speaker fees

- Amgen
- HEXAL
- MSD Sharp & Dohme GmbH
- Novartis Pharma
- Sanofi
- Vifor Fresenius Medical Care Renal Pharma

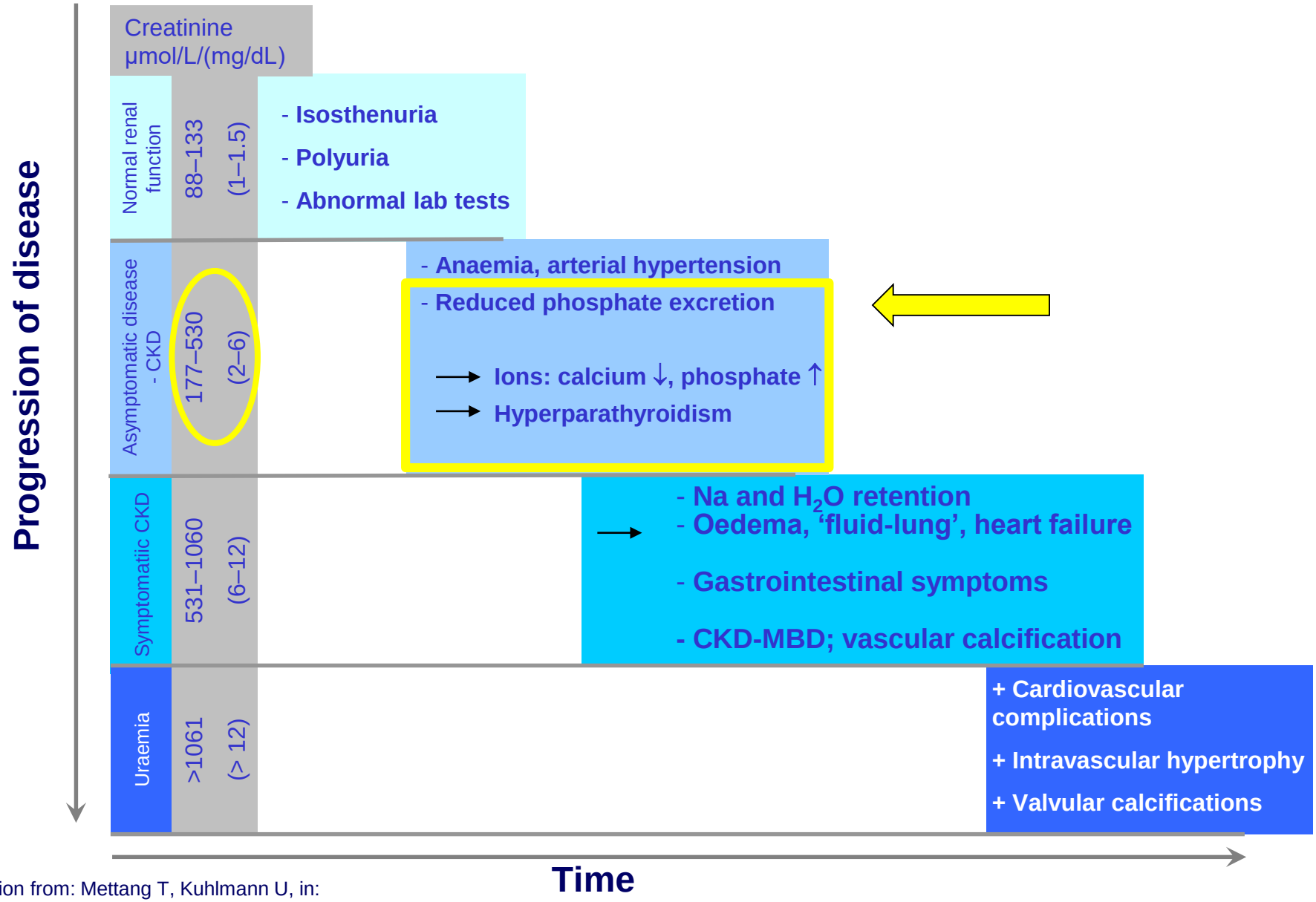
Hyperphosphataemia and CKD-MBD

Chronic Kidney Disease and Mineral and Bone Disorder

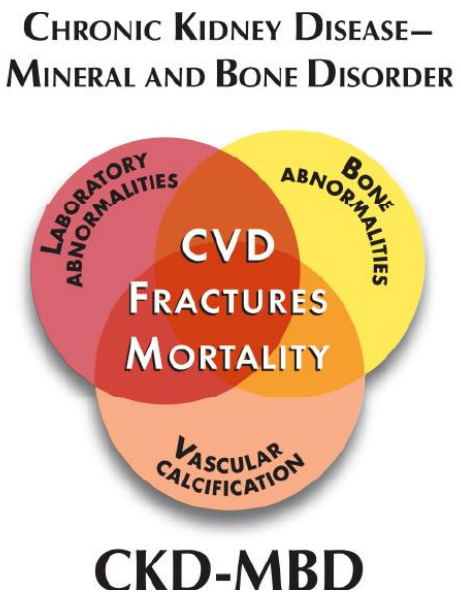
- Hyperphosphataemia is a common complication in patients with CKD[1]
- Hyperphosphataemia: → risk for cardiovascular disease and mortality[1]
- Treatment strategies and challenges:
  - Pill burden
  - Adherence
  - Patient education
- Need for multidisciplinary team care

1. Kestenbaum B, et al. J Am Soc Nephrol 2005;16:520–8

Complications in patients with chronic kidney disease



Modification from: Mettang T, Kuhlmann U, in:
Chapter: Chronische Niereninsuffizienz; Thieme Textbook, 2003; p311



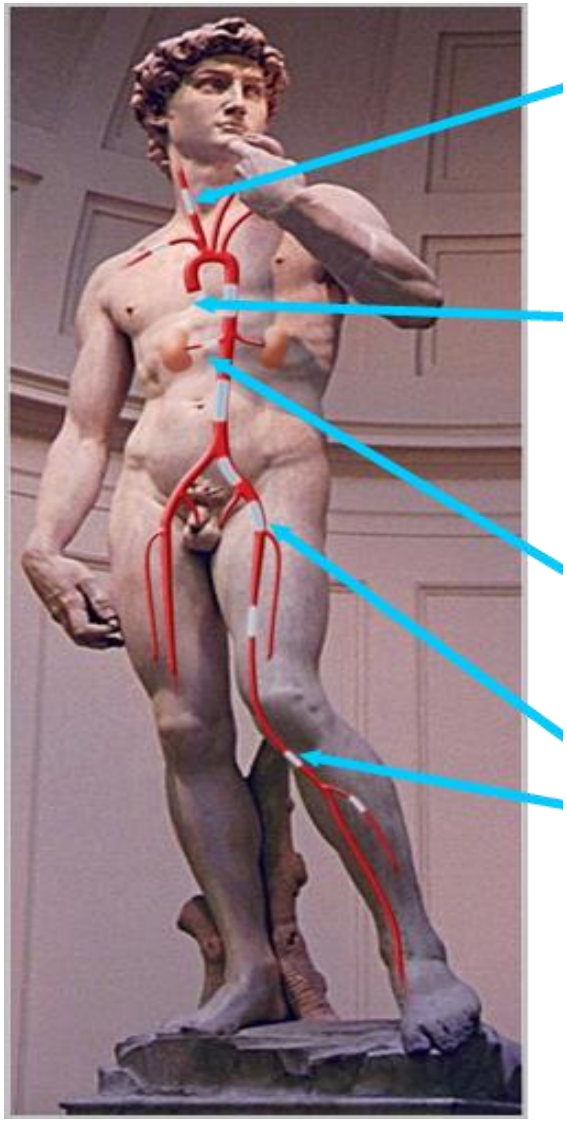
1. **'Asymptomatic' disease: lab tests – phosphate, calcium, iPTH**

2. **Renal osteopathy:** fractures, ossification of vessels and soft tissue

3. **Cardiovascular complications: atherosclerosis, valvular calcification**

iPTH, intact parathyroid hormone

Manifestation of atherosclerosis



Transient ischaemic attack
Ischaemic stroke

Angina pectoris
Myocardial infarction

Renovascular hypertension
Ischaemic renal injury

Peripheral arterial disease
Critical limb ischaemia

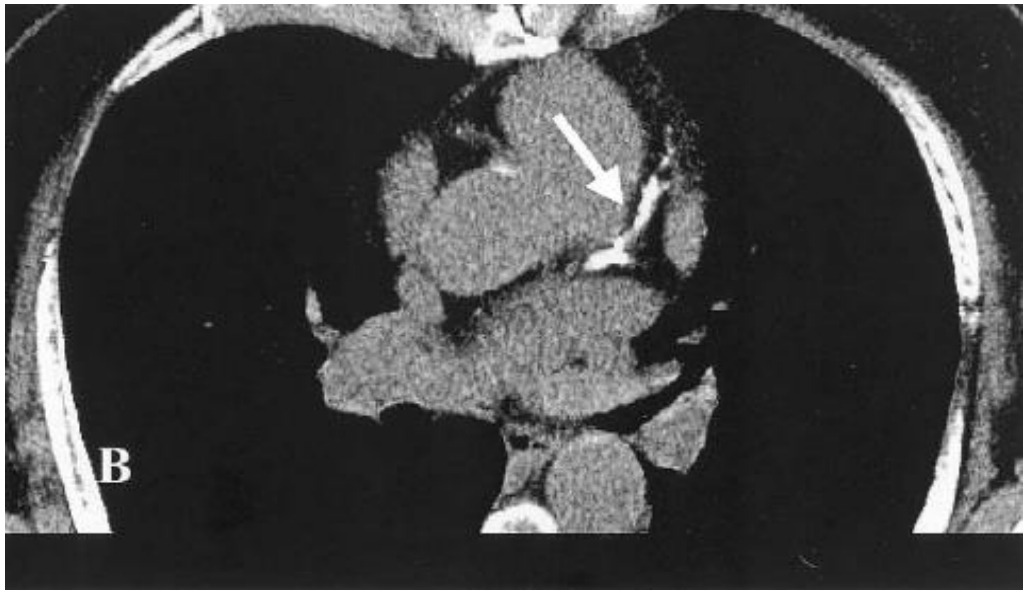
"Chronic kidney disease (CKD) is a worldwide public health problem of increasing prevalence and adverse outcomes, including progressive loss of kidney function, cardiovascular disease, and premature death."

Eknoyan G, et al. Foreword. In: Clinical Guide to the Basics of Bone and Mineral Metabolism in CKD. Ed: Olgaard K. Publ.: Kidney Disease: Improving Global Outcomes. 2006

CKD → vascular calcification → cardiovascular complications

Coronary calcification is very common in haemodialysis (HD) patients and is often associated with cardiovascular events (myocardial infarction, acute coronary syndrome [ACS])

CT – n=205 HD patients (~57 years, 64% ♂, 30% diabetes)

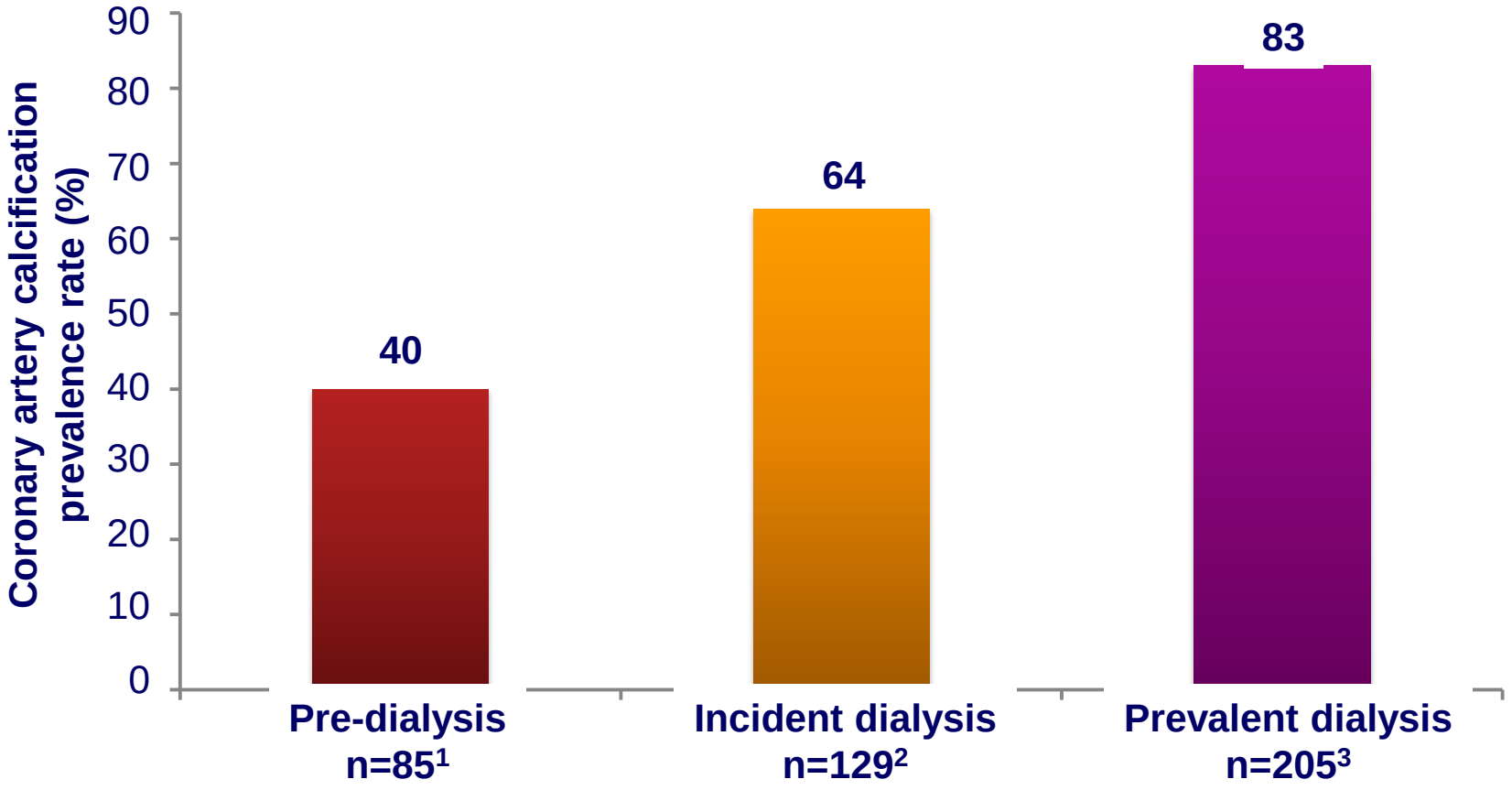


CT, computed tomography

Raggi P, et al. J Am Coll Cardiol 2002;39:695–701

Coronary heart disease in CKD

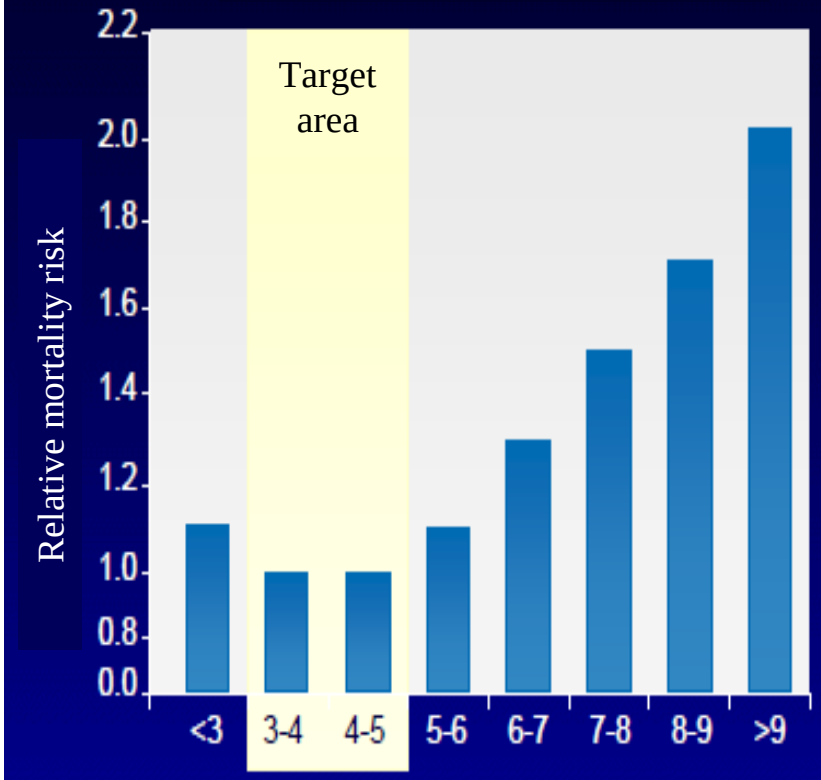
Three independent studies showed that the majority of patients on dialysis have coronary artery calcification



1. Adapted from: Russo D, et al. Am J Kidney Dis 2004;44:1024–30;
2. Adapted from: Spiegel DM, et al. Hemodial Int 2004;8:265–72;
3. Adapted from: Raggi P, et al. J Am Coll Cardiol 2002;39:695–701

Hyperphosphataemia increases mortality risk in HD patients

40,538 patients, FMC, USA

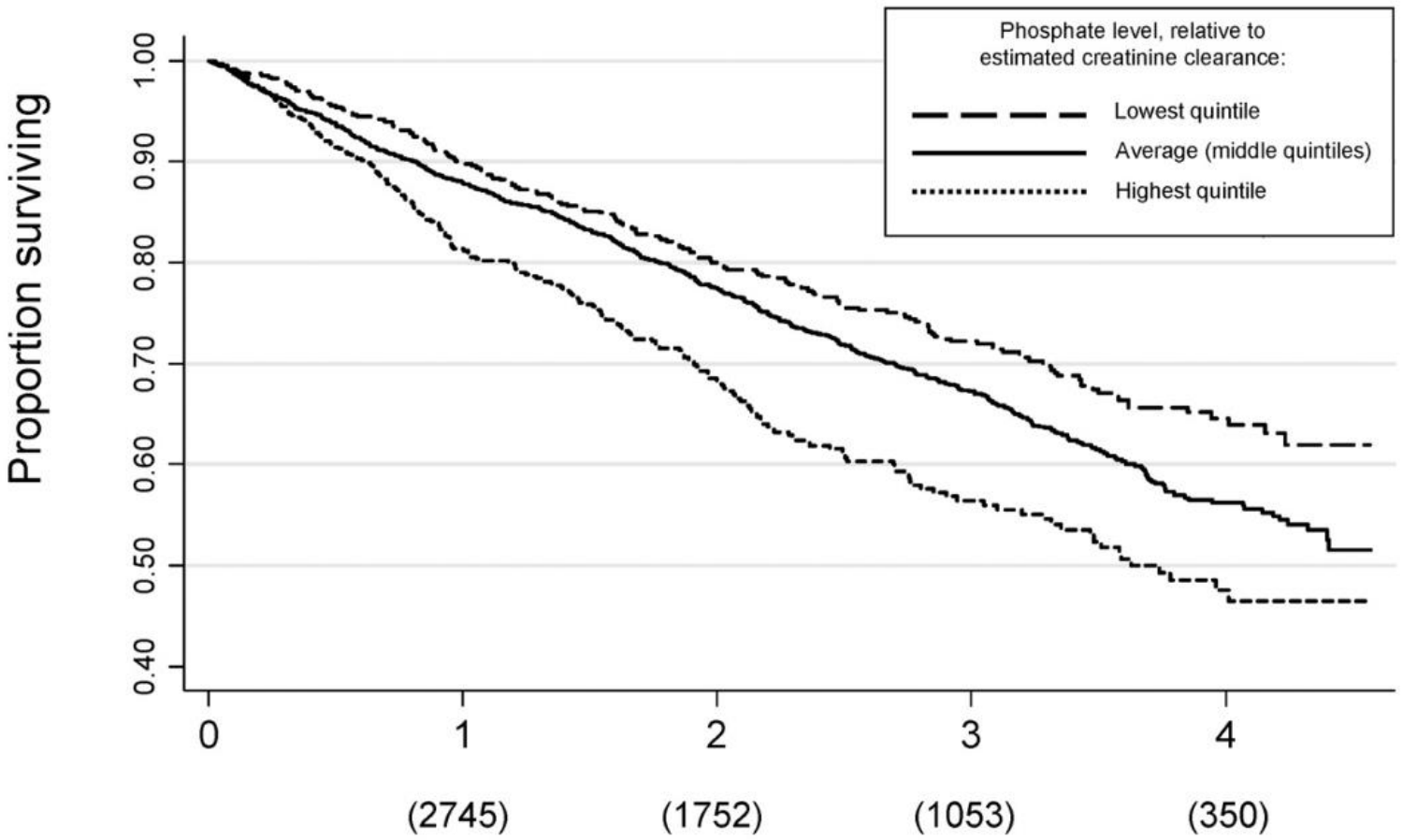


Raised phosphate		
	P_i ~5.5 mg/dL	Ca x P ~55 mg^2/dL^2
France	45,1	38,0
Germany	69,6	56,5
Italy	37,8	35,1
Japan	55,6	43,1
Spain	46,4	43,2
England	50,8	44,9
USA	52,0	43,8

DOPPS II Data

Block GA, et al. J Am Soc Nephrol 2004;15:2208–18

Phosphate and mortality in patients with CKD



Mortality ratio ↑
With P >3.5 mg/dL (1.4 mmol/L)

Kestenbaum B, et al. J Am Soc Nephrol 2005;16:520–8

Management of hyperphosphataemia

1.

Dietary phosphorus restriction

2.

Dialysis

3.

Phosphate binders

Serum phosphorus levels in dialysis patients can usually not be adequately controlled through dialysis and dietary restriction alone. Therefore, almost all dialysis patients need phosphate binders to limit their intestinal absorption of dietary phosphorus

Covic A, et al. Semin Dial 2007;20:158–69;
National Kidney Foundation. Am J Kidney Dis 2003;42(Suppl 3):S1–202

Phosphate-restricted diet

- Problems:
  - Patient acceptance
  - Beware: malnutrition

Phosphate-restricted diet

- Problems:
  - Patient acceptance
  - Beware: malnutrition

Therapeutic strategy: KDIGO summary

Phosphorus	Calcium	PTH
Aim = normal	**Calcification represents highest risk** **Detect with X-ray or ultrasound** **Restrict calcium in** **1. Hypercalcaemia** **2. Calcification** **3. Low PTH** **4. Abdominal calcifications**	**Evaluate PTH in context of hyperphosphataemia, hypocalcaemia, vitamin D deficiency** **Marked changes should trigger treatment changes** **Decrease cinacalcet in event of hypocalcaemia**

Treat the trends: Treat P and Ca to normal, PTH to goal

Kidney Disease: Improving Global Outcomes (KDIGO) CKD-MBD Work Group. Kidney Int 2009;76(Suppl 113):S1–130

Therapeutic strategy: KDIGO summary

Phosphorus	Calcium	PTH
Aim = normal	presents risk Detect with X-ray or ultrasound Restrict calcium in 1. Hypercalcaemia 2. Calcification 3. Low PTH 4. Abdominal calcifications	Evaluate PTH in context of hyperphosphataemia, hypocalcaemia, vitamin D deficiency Marked changes should trigger treatment changes Decrease cinacalcet in event of hypocalcaemia

New guidelines July 2017:
Restrict Ca-containing P-binders

Treat the trends: Treat P and Ca to normal, PTH to goal

Kidney Disease: Improving Global Outcomes (KDIGO) CKD-MBD Work Group. Kidney Int 2009;76(Suppl 113):S1–130
Ketteler M, et al. Kidney Int 2017;92:26–36

Management of hyperphosphataemia

DIALYSIS

Phosphate – intake and excretion

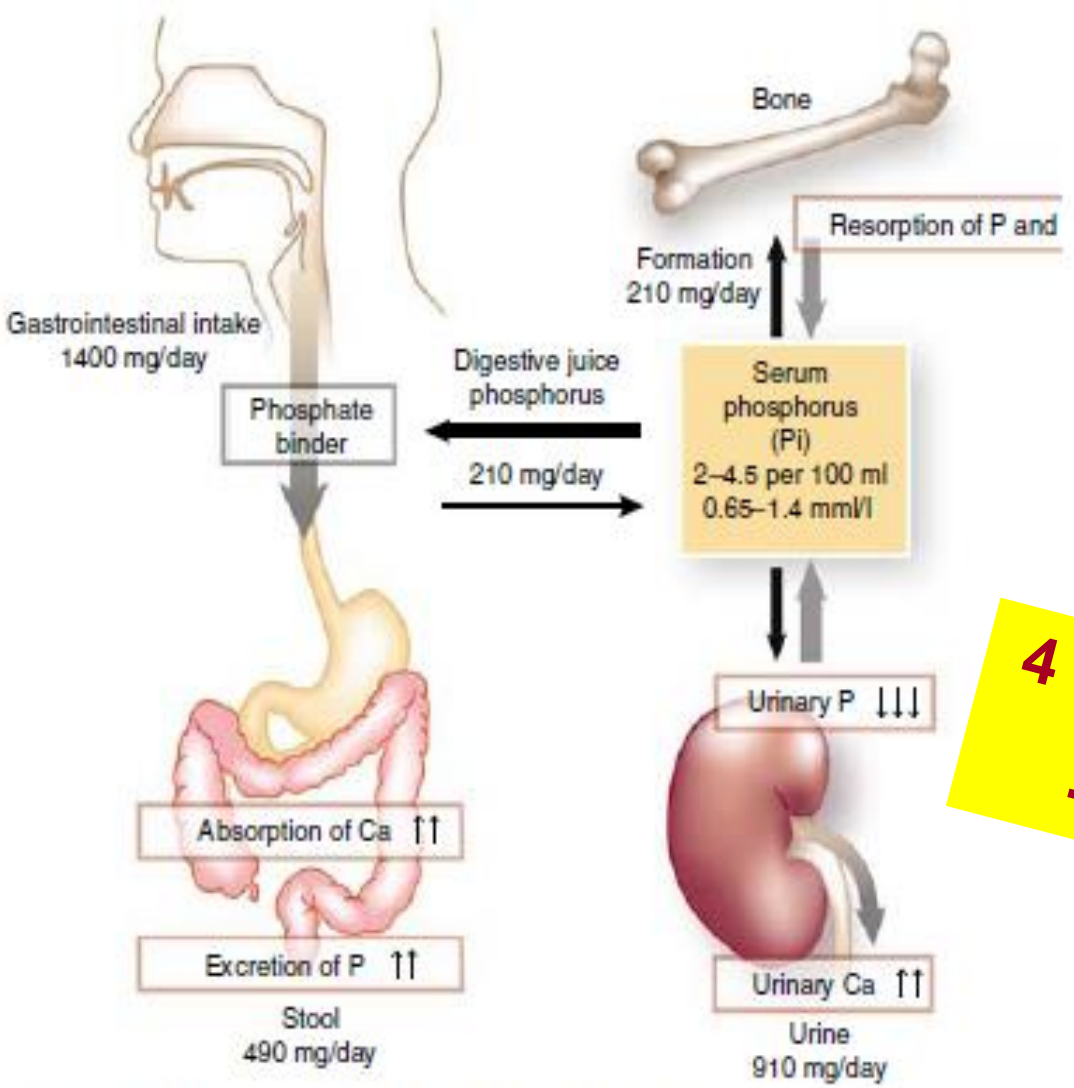


Figure 1 | Effects of oral phosphate binders.

4 hour dialysis: -1000 mg P

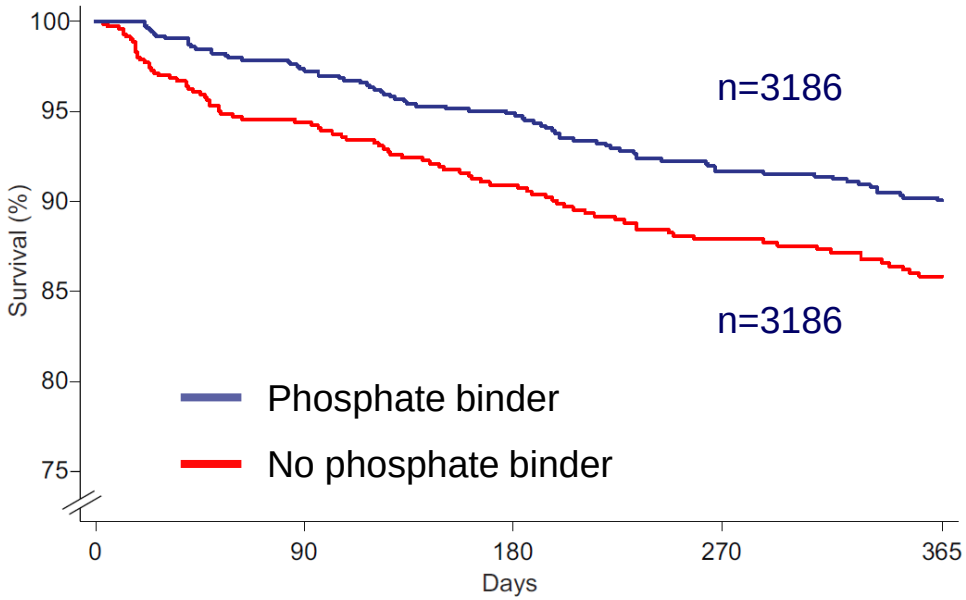
Hutchison AJ. Kidney Int 2009;75:906–14

Phosphate binders and survival on haemodialysis

Prospective, observational study

- Phosphate binder used
  - 40% calcium
  - 40% sevelamer
  - 20% lanthanum
  - Combinations

Phosphate binder: 136 vs 235 deaths per 1000 patient-years



Isakove I, et al. J Am Soc Nephrol 2009;20:388–96

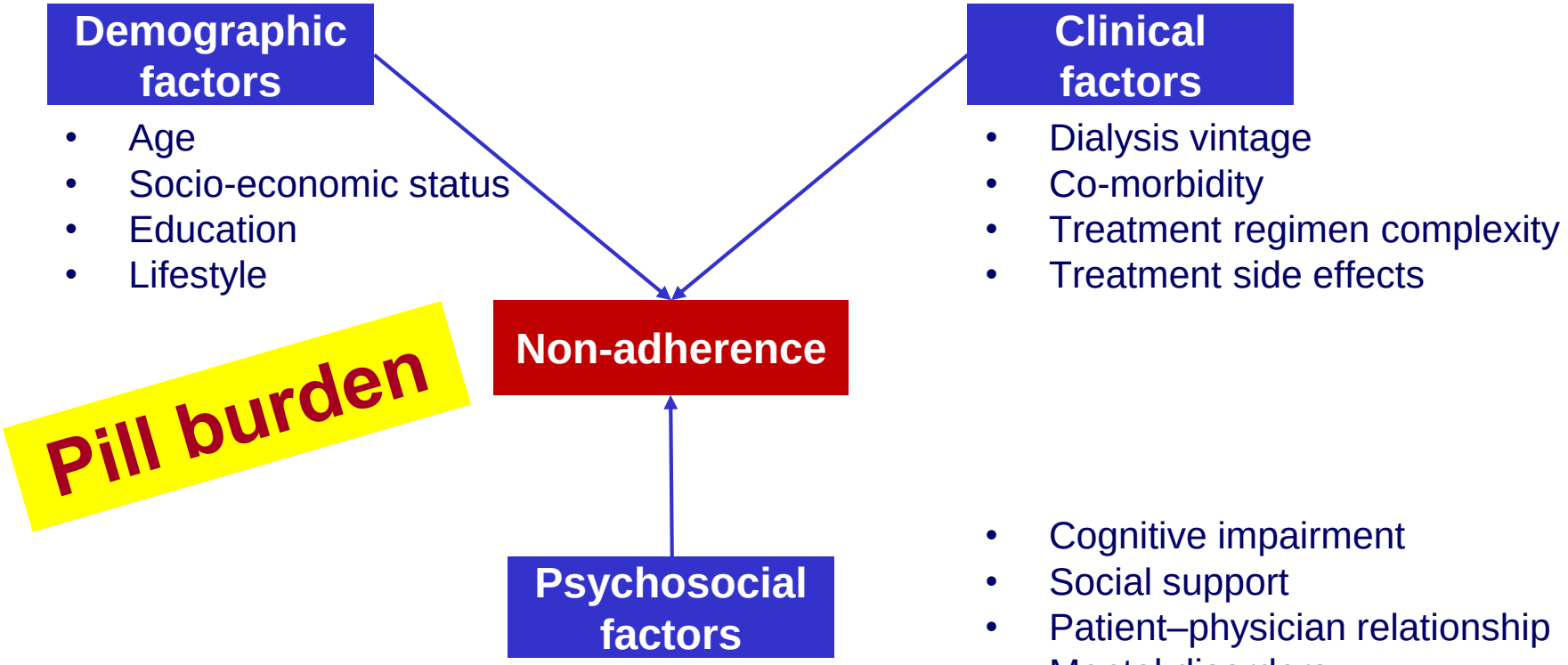
Comparison of available phosphate binders

	Effective	Pill burden	Pleiotropic effects	Accumulation	Cost
Aluminium	Yes	Low	None	Yes	Low
Calcium-Ac/Carb	Yes	High	None	Yes	Low
Sevelamer	Yes	High	Yes	No	High
Lanthanum	Yes	Low	None	Some	High
Ca-Mg	Yes	High	None	Some	Low
~~**Colestilan**~~	Yes	High	Yes	No	High
Fe-citrate	Yes	High	None	Yes	?
Fe-oxyhydroxide	Yes	Low	None	No	High

Adapted from Floege J. J Nephrol 2016;29:329–40

Factors associated with non-adherence in HD patients

Treatment adherence is multifactorial



Adapted from Schmid H, et al. Eur J Med Res 2009;14:185–90

Medication – adherence

Medication adherence: use of pharmacotherapy ↔ comply with instructions and realise it

- The WHO defines adherence as
  "the extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes – corresponds increasing the effectiveness of adherence with agreed recommendations from a healthcare provider"

"interventions may have a far greater impact on the health of the population than any improvement in specific medical treatments"

World Health Organization (WHO) 2003. Adherence to long-term therapies.
Available at http://apps.who.int/medicinedocs/en/d/Js4883e/. Accessed July 2017.

The problem of non-adherence

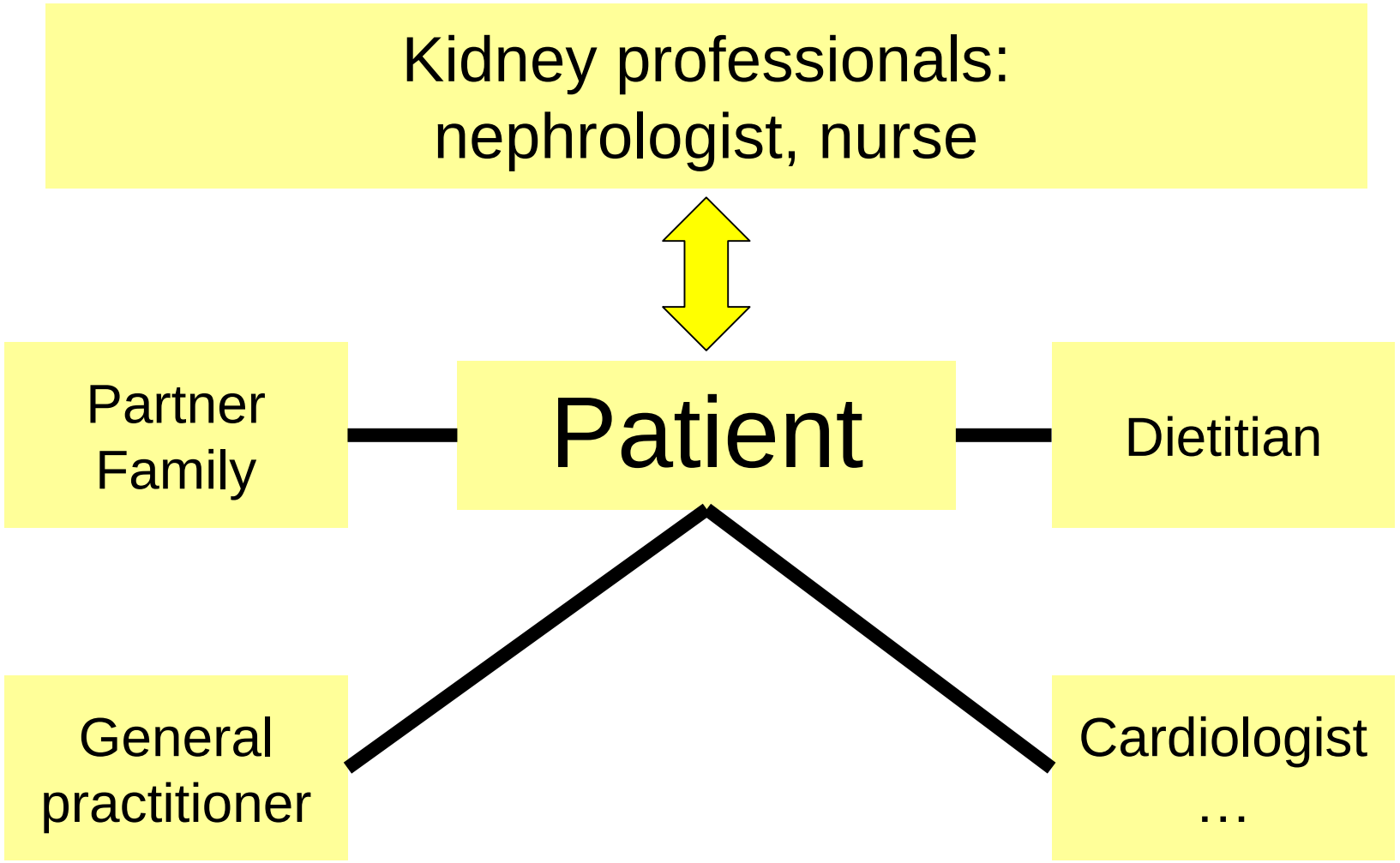
- Estimated that at least 30–50% medicines prescribed for long-term illnesses are not taken as directed

- This represents:
  - Progression of disease
  - Higher mortality
  - Costs for healthcare system

WHO 2003. Adherence to long-term therapies. Available at http://apps.who.int/medicinedocs/en/d/Js4883e/. Accessed July 2017.

Adherence: who cares?

Adherence: who cares? = teamwork



Summary – take home messages

- Hyperphosphataemia is very common and a major risk factor for premature vascular calcification in CKD patients
- Phosphate binders are very valuable for reaching treatment goals
- Adherence is the groundwork for therapeutic success
- Communication and patient motivation are very important:

  → multidisciplinary team is necessary ←

Cernaro V, et al. J Nephrol Renovasc Dis 2016;9:11–9

Patient education and motivation: the role of the renal nurse

Stefaan Claus
Belgium

Patient education and motivation: the role of the renal nurse

Stefaan Claus
University Hospital Ghent, Belgium

CHZH/VEL/17/0249b

Disclosures

- Vifor Fresenius: sponsor of this meeting
- Bellco: advisor in development of the CARPEDIEM™

Multidisciplinary team (MDT)

MDT alignment

↓

Right people
Right key worker
Right plan

↓

Who's doing what…?

What role can a nurse play?

- Statement: nurses know the person who has the disease not just the disease the person has
  - Frequent and longer patient–nurse contact
  - Social and psychological factors

- ISN
- KDOQI
- EBPG

} What is the role of the nurse?

EBPG, European Best Practice Guidelines; ISN, International Society of Nephrology; KDOQI, Kidney Disease Outcomes Quality Initiative.

Pitfalls

Misplaced care:

"Things look OK then we can pretend they are OK"
= compassion driven

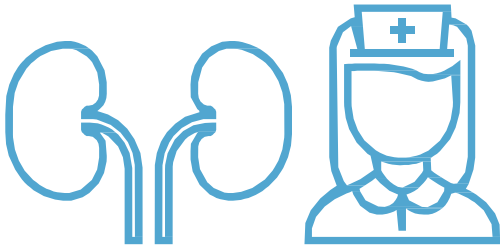
Misplaced treatment:

"If the bloods are OK, then at least I've done my job OK."
= disease driven

Basic requirements!

- Education on ‘mineral and bone disorders’
- Support of the industry (webinars?)
- Time!!!

Chronic kidney disease and lifestyle



Nurse guide for adult patient education*

*This content reflects the guidance contained in nice.org.uk/guidance/cg182. July 2014.
This resource was developed via a systematic literature search. Each statement or claim is supported by a reference, contained in the material.

Patient education

Have a conversation with your adult CKD patients and help them understand the benefits of:

- A suitable **diet**[1]
- A healthy **lifestyle**[2]
- Adherence to **medication** and therapy[3]

An educational conversation with a nurse, who is actively listening, can help patients:[4,5]

- By providing them with skills to better manage their condition
- Follow their treatment plan
- Feel supported

1. Sinha A, Prasad N. Clin Queries Nephrol. 2014;3:38–45. 2. Darren ER et al. CMAJ. 2006;174:801–809.
3. Van Camp YP et al. J Nephrol. 2014;27:673–679. 4. Stumm EMF et al. Rev Bras Enferm. 2017;70:26–33.
5. Toussaint ND et al. Nephrol Dial Transplant. 2011;26:1319–1326.

Diet and food

Low-phosphate diets

- Patients with damaged kidneys have difficulty regulating their phosphate levels[1]
- Following a low-phosphate diet can help CKD patients control their phosphate levels[2]

Patients should:

- **Eat a mixed diet** of fruit, vegetables, meat and poultry[2]
- **Ask** a dietitian for help with a healthy eating plan[2]

1. Lederer E. Hyperphosphatemia. Available at: http://emedicine.medscape.com/article/241185-overview. Accessed April 2016.
2. Sinha A, Prasad N. Clin Queries Nephrol. 2014;3:38–45.

Diet and food

Patients should:

Watch out for processed foods

- These often contain additives and hidden phosphates[1]

Avoid e-numbers[1,2]

- E338–343
- E450–458
- E540–545

Avoid[1]

- Processed food
- ‘Fast food’
- Carbonated drinks

Cooking tip:

Patients can reduce the phosphate level in food by soaking or boiling[1]

Boil **Soak**

1. Sinha A, Prasad N. Clin Queries Nephrol. 2014;3:38–45. 2. D’Alessandro C et al. BMC Nephrol. 2015;16:9.

Lifestyle and exercise

Exercise is good for patients as it can:[1]

- Strengthen bones[1]
- Reduce stress[1]
- Help protect mental health[1]

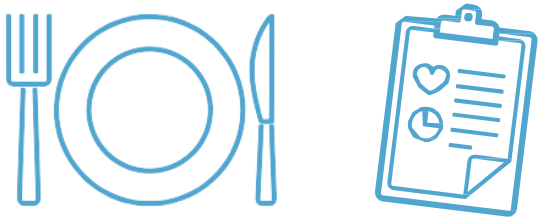
Non-dialysis patients can exercise at a moderate intensity[2]

1. Darren ER et al. CMAJ. 2006;174:801–809. 2. Johansen LK et al. Am J Kidney Dis. 2012;59:126–134.

Lifestyle and exercise

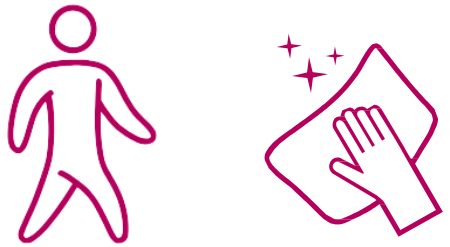
Patients should:

- Eat well[1]
- Follow prescribed therapies[2]
- Not smoke[3]
- Exercise[4]



Dialysis patients can enjoy gentle exercise, such as:

- Walking
- Light cleaning



A structured, 15-minute regular exercise programme during dialysis based on the patient's capacity can improve dialysis efficacy[5]

1. Sinha A, Prasad N. Clin Queries Nephrol. 2014;3:38–45. 2. Van Camp YP et al. J Nephrol. 2014;27:673–679.
3. Yacoub R et al. BMC Public Health. 2010;10:731. 4. Darren ER et al. CMAJ. 2006;174:801–809.
5. Mohseni R et al. Oman Med J. 2013;28:345–349.

Phosphate binders

- Phosphate binders are medicines that help lower blood phosphate levels[1]
- They are required by the majority of patients on dialysis[1]
- Patient preference and adherence to prescribed therapy is as important as the efficacy of the prescribed binder[1]

Hyperphosphataemia

- Hyperphosphataemia in dialysis patients is mainly attributed to non-adherence of diet, prescribed phosphate binders or both[2]

Leaving hyperphosphataemia uncontrolled can lead to serious health complications such as cardiovascular disease, vascular calcification, and weakened joints and bones[3–5]

1. Hutchison AJ et al. Nat Rev Nephrol. 2011;7:578–589. 2. Sherman R. Am J Kidney Dis. 2016;67:182–186.
3. Lederer E. Hyperphosphatemia. Available at: http://emedicine.medscape.com/article/241185-overview. Accessed April 2016.
4. Penido MG, Alon US. Pediatr Nephrol. 2012;27:2039–2048. 5. Tonelli M et al. Circulation. 2005;112:2627–2633.

Adherence to medication

Patients should:

Take medication with food as recommended:[1–6]

- Studies have shown that taking treatment as recommended can help patients to:[7]
  - Stay healthier for longer
  - Have a better quality of life

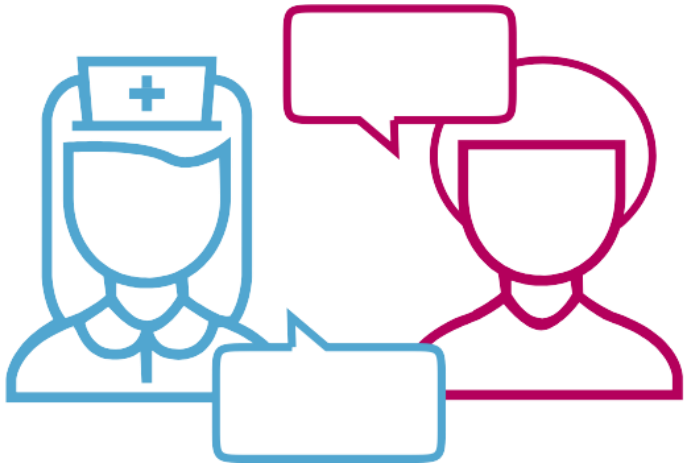
Speak to a nurse about side effects

- Gastrointestinal side effects are common when taking phosphate binders
- Common side effects can include:
  - Nausea[2–6]
  - Vomiting[3–6]
  - Constipation[1,2,4,6]
  - Diarrhoea[2–4,6]

1. Alu-cap, https://www.medicines.org.uk/emc/PIL.3896.latest.pdf. 2. Calcichew, https://www.medicines.org.uk/emc/PIL.28517.latest.pdf.
3. Fosrenol, https://www.medicines.org.uk/emc/PIL.19996.latest.pdf. 4. Phosex, https://www.medicines.org.uk/emc/PIL.26329.latest.pdf.
5. Renagel, https://www.medicines.org.uk/emc/PIL.18547.latest.pdf. 6. Velphoro, https://www.medicines.org.uk/emc/PIL.29564.latest.pdf.
7. Van Camp YP et al. J Nephrol. 2014;27:673–69.

Time to talk?

- **Non-adherence** to diet and/or prescribed phosphate binders can lead to hyperphosphataemia in dialysis patients[1]
- To best manage their conditions, patients need to understand their active role in their health[2]



Renal nurses are often in the important position to identify, monitor and educate their patients, and help them improve their quality of life

1. Sherman R. Am J Kidney Dis. 2016;67:182–186. 2. Toussaint ND et al. Nephrol Dial Transplant. 2011;26:1319–1326.

Remember

Patients can help manage their condition by:

- Eating a suitable diet[1]
- Leading a healthy lifestyle[2]
- Following prescribed treatment and therapies, as recommended[3]

1. Sinha A, Prasad N. Clin Queries Nephrol. 2014;3:38–45. 2. Darren ER et al. CMAJ. 2006;174:801–809.
3. Sherman R. Am J Kidney Dis. 2016;67:182–186.

Take-home messages

- Nurses have an important role in management of hyperphosphataemia
- Balance: ‘misplaced care’ and ‘misplaced treatment’
- Guide the patient in the treatment of CKD

Good enough means the best possible!

Panel discussion

Closing the circle

Isabel Walker
UK

Thank you