非癌症末期病人／家屬之需求與照顧-以末期腎臟病患為例-

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ESRD治療模式

- 血液透析(H.D.)
- 腹膜透析(CAPD)
- 腎臟移植

- 支持療法
  * 飲食療法
  * 症狀控制
  * 控制血壓及代謝問題
  * 防治併發症
  * 緩和照護

慢性腎病分期

	肌酸酐清除率：毫升/分	防治目標
1	＞90	1.篩檢：確立診斷 2.找出危險因子
2	60-89	1.防治疾病（全人） 2.減低危險因子 3.延緩惡化 4.防治併發症
3	30-59	
4	15-29	準備替代療法
5	＜15	透析/移植

Palliative Care Model of ESRD

curative

bereavement

1. Screening and investigation of CKD
2. Management of reversible factor

Dialysis and Transplant
- Life-prolonging
- Quality of life
- Terminal care

Supportive therapies**: palliative, rehabilitation, spiritual

**Anemia management, access, nutrition, BP control, advance care planning, etc.

•Modified from Sheffield model of chronic disease, and Jean L. Holley

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末期腎臟病ESRD=CKD5

1.PREDIALYSIS PATIENT

2.DIALYSIS PATIENT

3.TERMINAL DIALYSIS PATIENT

台灣三高增加心腦腎病

	腦中風	CKD	冠心症
糖尿病	2.9	2.4	1.5
高血壓	2.8	1.7	1.9
高血脂	2.4	1.6	1.8

	滿足需求	提昇療護與生活品質保健
PREDIALYSIS	保健 延緩透析來臨	1. 衛教 2. 協助自我
DIALYSIS	好的透析品質	1. 解釋檢驗報告 2. 建議改善方針
TERMINAL	善終	1. 停止透析 2. 提供安寧臨終照護

台灣透析病人現況

1.盛行率與新增病人全球第一

2. 約6萬人透析. 92%HD. 8%CAPD

3. 每年增加約5000人

4. 健保費用一年338億

5. 開始透析年齡:60歲

6. 50%活8年半

7. 家庭支持照顧良好

8. 新增病人以糖尿病最多

透析病人/家屬需求

1.優良的透析品質—減輕症狀.痛苦

2. 醫護人員多關懷

醫師的關懷.鼓勵.提昇病人/家屬的自我照顧及生活品質

3. 瞭解定期的檢驗報告

4. 協助病人透過飲食.藥物.運動諮詢，盡力達成好的透析品質

Indications of Dialysis in ESRD

- Pericarditis
- Fluid overload or pulmonary edema
- Progressive uremic encephalopathy
- Bleeding diathesis attributable to uremia
- Persistent nausea 、vomiting and Anorexia
- Plasma ***creatinine*** concentration >***10-12*** mg/dl or ***BUN*** >***100*** mg/dl
- Persistent pruritus or restless leg syndrome

Lift threatening complications of ARF

- 1.acute pulmonary edema
- 2.Hyperkalemia
- 3.Metabolic acidosis

慢性腎衰竭及腎衰竭，未明示者(一)

- 本項適用主診斷585 (慢性腎衰竭 ；chronic renal failure) 及 586 (腎衰竭，未明示者； renal failure , unspecified) 兩項疾病末期定義：

1. 慢性腎臟病至末期腎臟病階段，尚未接受腎臟替代療法病患，屬慢性腎臟病 (CKD) 第 4，5 期病患 (GFR <30 ml/min/1.73m2) ，或已接受腎臟替代療法(血液透析、腹膜透析、腎臟移植) 病患。
2. 病人因嚴重之尿毒症狀，經原腎臟照護團隊評估病患可能在近期內死亡。

慢性腎衰竭及腎衰竭，未明示者(二)

3. 病人在自由意識的選擇與自主的決定不願意，或因合併下列疾病狀況之一，不適合新繼續接受長期透析治療或接受腎臟移植者：
   - 其他重要器官衰竭及危及生命之合併症
   - 長期使用呼吸器
   - 嚴重感染性疾病合併各項危及生命之合併症
   - 惡病質、或嚴重之營養不良危及生命者
   - 惡性瘤瘤末期患者
   - 因老衰、其他系統性疾病，生活極度仰賴他人全時照顧，並危及生命者

急性腎衰竭，未明示者(一)
(acute renal failure, unspecified)

1. 已接受腎臟替代療法 (血液透析、腹膜透析、腎臟移植) 病患。
2. 病人因嚴重之尿毒症狀，經原腎臟照護團隊評估病患可能在近期內死亡。

急性腎衰竭，未明示者(二)
(acute renal failure, unspecified)

3. 病人在自由意識的選擇與自主的決定不願意，或因合併下列疾病狀況之一，不適合繼續接受長期透析治療或接受腎臟移植者：

- 其他重要器官衰竭及危及生命之合併症
- 長期使用呼吸器
- 嚴重感染性疾病合併各項危及生命之合併症
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Component of P.C in ESRD

1. Pain and symptom management
2. Advance care planning
3. Psychosocial and spiritual support
4. Ethical issue in dialysis

- Shared decision-making in the appropriate initiation of and withdrawal from dialysis

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Definition of ACP (advance care planning)

- ACP is a process of communication among patients, families , health care providers, and other important individuals about the patient's preferred decision-maker and appropriate future medical care if and when a patient is unable to make his or her owe decisions

Components of ACP (→)

1. The document: instruction directives are developed in accord with the person's wishes, values, life goals
2. The participants: patient-family. Physicians and or dialysis unit staff to initiate discussions of ACP and advance directives

Components of ACP (二)

3. The purpose:

- Completion of a written advance directive
- Prepare for death
- Strengthen relationships
- Relieve burdens on loved ones

Usefulness of ACP in the ESRD population

- Decision making easier if ACP has occurred and advance directives exist
- Who have advance directives experience better, more reconciled deaths
- Avoid futile end-of-life therapeutic interventions

預備與抉擇

- 預立遺囑
- 預立醫療委任代理人書
- 預立選擇安寧緩和醫療意願書
- 選擇安寧緩和醫療意願書
- 預立不施行心肺復甦術意願書
- 不施行心肺復甦術意願書

6 markers of good practice of stopping dialysis

1. Access to communication skills and knowledge of symptom control
2. Offering prognostic assessment
3. Timely information and joint palliative care plan
4. Ongoing medical care for patients option not to dialyse
5. Dying with dignity
6. Culturally appropriate bereavement support

http://www.kidney.org.uk/Medical-Info/other/discontinuing-treatment.html

Preparing to stop Dialysis

- Early discussion
- Dialysis seminars
- Treatment plan

Early discussion

- Benefits, harms and limits of dialysis.
- Time- limited benefit.
- Religious and culture factors.

Dialysis seminars

- Provide information on tech and scientific aspect of dialysis.
- Aid patient and families dealing with physical, emotional and spiritual problems related to illness.
- Develop mutual trust become friends.

Treatment plan

- Use dialysis
- Medical indications for stopping dialysis.
- DNR
- Emphasize stopping dialysis may avoid futile suffering and lead to dignified and “good” death.

  * death usually rapid (mean 8.2 days)

  * relatively little suffering

ESRD End-of-Life Symptom Management (→)

1. Pain: WHO guidelines
    (1) Fentanyl: drug of choice
    (2) Morphine: reduce dosage
    (3) Meperidine contraindicated
2. Myoclonic jerks: benzodiazepines, eg, lorazepam

ESRD End-of-Life Symptom Management (二)

3. Hunger and thirst: full diet if desired
4. Dyspnea: Opioids and ultrafiltration if necessary to avoid pulmonary edema
5. Excessive secretions : Scopolamine

JAMA 2003; 289:2113-19

基本資料:美加八家透析中心131病患(Dialysis Discontinuation and palliative care)

AJKD Jul 2000

- 女:男=6:4
- 白人73% 、黑人22% 、其他6%
- 年齡:平均70歲(17-89歲)
- 透析歲月:平均34月(3-167月)
- CRF原因:1. DM(46%) 2. HT(29%)
  3. GN(10%)
- 透析方式:1. HD(83%) 2. CAPD(11%)
  3.CCPD(5%) 4. Home HD(2%)

Comorbidity

- 77% dialysis patients had 3-7 comorbidities

  1. Neurological : 64%

  2. C.V. : 63%

- Specific comorbidity

  1.CAD : 50%

  2. PVD : 50%

  3. poorly controlled HT : 38%

Reason of withdraw from dialysis

- Autonomy and belief of patients families.
- Promise of a good death by physician.

Consciousness level

48 hours after withdrawal from dialysis

- alert : 43%
- somnolent : 46%
- coma : 11%

Symptoms during the last 24 hours amo 79 patients follows up

Symptom	Present (%)	Severe (%)
Pain	42	5
Agitation	30	1
Myoclonus or muscle twitching	28	4
Dyspnea or agonal breathing	25	3
Fever	20	-
Diarrhea	14	1
Dysphagia	14	-
Nausea	13	1

Treatment

- Medication

  1. pain medication : 87% at least one occasion

  2. analgesic : 9%

  3. no pain medication : 4%

- O2 therapy : 22%
- Ultrafiltration for pulmonary distress : None

Place of terminal care

- Hospital : 61%
- Nursing home : 24%
- Inpatient hospice : 2%
- At home : 13%

Good death

- Effectiveness : 93% (from caregiver and/or families)
- Die alone : 29%

  Families and/or staff present 71%
- mean survival time 8.2 days.

  1. 50% within 6 days
  2. 5 patients in 30-46 days
  3. 10 patients <2 days

Incorporating Palliative Care into Dialysis Unit

- Educational in-services on palliative care topics
- Advance care planning
- Pain & symptom assessment and treatment protocols
- Communication of prognosis and changes in condition
- Referral to hospice when terminally ill
- QI with review of quality of death

Shared Decision-Making in the Appropriate Initiation of and withdrawal from dialysis

- Shared Decision-Making
- Informed Consent or Refusal
- Estimating Prognosis
- Conflict Resolution
- Advance Directive
- Withholding or Withdrawing Dialysis
- Special Patient Groups
- Time-Limited Trials
- Palliative Care

RPA/ASN. 2000.

案例 1

- 張女士 69歲 DM, Triopathy, ESRD, CHF_{FC} III, CAD & TVD S/P CABG , PAOD, gangrene of toes. Cr:3.9， 即使使用最大劑量之利尿劑，每日排尿量少於50ml ，常因肺水腫反覆入院，血液透析後，心衰竭現象有改善。(建議長期血液透析，使體內水份保持平衡。)

案例 2

- 陸先生 47歲 末期腎病長期接受血液透析，因嚴重背痛，胸腰椎X光顯示T6,T9,T11,L2壓迫性骨折及骨鬆症，於95年1月18日入院接受核磁共振檢查及治療，住院第八日(即95年1月25日)上洗手間時突發意識昏迷，四肢無力，瞳孔對光反應微弱，經插管急救，轉入ICU ，CT顯示中腦和小腦大量出血，漫延到大腦室，緊急會診神經外科。

案例 2

- 外科醫師告訴家屬病情不適開刀，預後不好。當時意識昏迷，靠昇壓藥維持血壓，與呼吸器維生。與家屬充分溝通後，延後一天血液透析，隨後病情惡化，家屬同意DNR ，終止血液透析後第四天即往生。

案例 3

- 李先生，73 歲, hepatoma, liver cirrhosis, ascites , splenomegaly ,thrombocytopenia . 因牙齦不停地流血及腹瀉而入院。住院時 Cr:3.0(CKD stage IV), Ht : 224%, platelet : 25000/mm3. 經過輸血小板及冷凍血漿等支持療法。第四天，creatinine 漸漸上升到 7.9mg%, CCr= 7ml/min ; 同時發燒40C，CXR – acute pulmonary edema, r/o sepsis , 有呼吸衰竭現象 。

案例 3

- 給予插管及呼吸器的補助治療。同時又合併急性腎衰竭，第六天，creatinine :12mg% , 與家屬溝通後，先後以血液透析治療共六次。最後，因併發 pneumonia , hepatic encephalopathy , deep coma ; 與家屬溝通後，停止 HD。四天後往生。

案例 4

- 陳女士、82歲、polio, bilateral femoral neck fracture, CKD-stage V, CHF (Fc III-IV) , bilateral pleural effusion, myelodysplastic syndrome. 98年4月 2日 因 shortness of breath, shock (r/o pneumonia) 入院。

案例 4

- 經治療六天病情改善而出院。98年4月 11 日因 OHCA , 經 CPR , 插管及接呼吸器緊急治療後而入院。當時creatinine :6.3mg% ; deep coma . 與家屬溝通後，決定palliative care , 而沒有 HD. 五天後往生。

Recommend To Palliative Care

- There is an option for ESRD patients who choose to stop or not to start dialysis: continued palliative care.
- 轉介安寧或共同照護。
- 提供居家療護。
- 對家屬的哀傷支持。

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curative

bereavement

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2. Management of reversible factor

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結論(一)TQM and CQI of ESRD

篩檢高危險群

1、**DM,HT,CVD,PAOD,Gout,Hyperlipidemia**

2、**FHx of renal disease**

3、**pre-HT,pre-DM,MS,obesity**

4、長期服用不明藥物或保健食品,抽菸,嚼檳榔

↓

早期診斷並治療可恢復的腎病

↓

確立**CKD**分期,執行各期照護

↓

找出並矯正腎功能惡化因素,並預防併發症

↓

準備替代療法

結論(二)ESRD照護的理念與目標

1、充實團隊能力，與病人分享保健保腎知識，鼓勵、協助病人自我照顧。

2、目標：整全的照護，不斷地品質改善，落實安寧照護理念：

四全/五全　全人照護

全程照護

全家照護

全隊照護

全民教育

ESRD安寧照護之結論

- 對末期腎臟病患，醫師宜充分向病患及家屬解釋治療方式及估計預後，一切以病患的利益和自主權著想，尊重病患選擇的治療方式。
- 適當機會或腎友聚會時，討論可能面臨的終止透析和CPR的議題。
- 團隊具備專業技能，尤其安寧緩和照護

  理念與能力，才能照顧病患，維持好的生命品質（善終）。
- 確保臨終者能安詳的往生，家屬能夠無憾平安地度過哀傷期，回歸有意義的生活。


謝謝大家聆聽
祝 大家
智慧慈悲又健康！
平安喜樂過百歲！